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ABSTRACT

The proceedings of public hearings on issues related to the care and treatment of institutionalized mentally disabled persons are presented. Among the issues addressed are physical abuse and maltreatment of residents, excessive restriction of patients' liberties, absence of programing, and efforts to remedy these problems. Documentation appended to Part 1 includes a report of the Joint Commission on Accreditation of Hospitals, and the responses of W. Bradford Reynolds to questions submitted by Senator Weicker on the report: "Staff Report on the Institutionalized Mentally Disabled." The staff report (printed separately as Part 2) presents findings from a study of environmental conditions and physical health and safety in state mental hospitals. Staff visited 31 facilities and conducted an estimated 600 interviews with staff, patients, residents, facility administrators, state and federal officials and others in the field. It was concluded that on many wards, parents/residents are vulnerable to abuse and serious physical injury; that hospital staff are also at risk of serious physical injury; and that living conditions in many institutions are unacceptable. Interviews also suggested that there is little treatment other than medication provided in many institutions. Monitoring information is reported in terms of accreditation and certification of state hospitals for the mentally ill, certification of institutions for the mentally retarded, and the Civil Rights of Institutionalized Persons Act. Further considerations for institutionalization of both the mentally ill and the mentally retarded are noted. The federal government's role with mental health systems is examined, including agency programs and federal initiatives. The final chapter reviews judicial decisions on constitutional rights of the mentally disabled, the right to treatment, and the right to refuse treatment. (CL)

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S. HRG. 99-50, Part 1

CARE OF INSTITUTIONALIZED MENTALLY DISABLED PERSONS

JOINT HEARINGS

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON
LABOR AND HUMAN RESOURCES

AND THE

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN
SERVICES, EDUCATION, AND RELATED AGENCIES

OF THE

COMMITTEE ON APPROPRIATIONS
UNITED STATES SENATE

NINETY-NINTH CONGRESS

FIRST SESSION

ON

EXAMINING THE ISSUES RELATED TO THE CARE AND TREATMENT OF THE NATION'S INSTITUTIONALIZED MENTALLY DISABLED PERSONS

APRIL 1, 2, AND 3, 1985

PART 1

U.S. DEPARTMENT OF EDUCATION
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CARE OF INSTITUTIONALIZED MENTALLY DISABLED PERSONS

MONDAY, APRIL 1, 1985

U.S. Senate, Subcommittee on the Handicapped, Committee on Labor and Human Resources, and Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Committee on Appropriations,

Washington, DC.

The subcommittees met, pursuant to notice, at 9:32 a.m., in room SR-428A, Russell Senate Office Building, Senator Lowell Weicker, Jr. (chairman of the Subcommittee on the Handicapped) presiding.

Present: Senators Weicker, Stafford, Thurmond, and Simon.

Also present: Senator Proxmire.

OPENING STATEMENT OF SENATOR WEICKER

Senator Weicker. The Subcommittee on the Handicapped of the Senate Committee on Labor and Human Resources and the Subcommittee on Labor, Health, and Human Services, Education and Related Agencies of the Appropriations Committee will come to order.

That is all right, Jonathan; you just enjoy yourself as much as any of us can in a Senate hearing.

I have a prepared statement, which I am going to enter into the record and would instead like to make a few extemporaneous remarks based on this hearing and my reading of the initial report put together by the investigative staff.

[The prepared statement of Senator Weicker follows:]

Prepared Statement of Senator Weicker

We are here this morning to begin to give the American people and the Congress an opportunity to look over the walls of our Nation's public institutions for the mentally disabled. Too often, as we will find out, the sight is a disgrace to us all.

Approximately six months ago, as chairman of the subcommittees with responsibility for the Nation's mentally ill and retarded, I asked staff to examine the issues related to the care and treatment of the Nation's institutionalized. This was a follow-up to nearly two years of hearings, investigations and other research.

As a parent and citizen, I have also been regularly shocked by reports in the media of physical abuse, violence and even death in State facilities for the mentally disabled.

Protection for these frailest of our society exists largely on paper. From the walls of the nurses' stations to the halls of Federal agencies, my staff has seen carefully written rules and procedures.

But they have also seen fear in the eyes of patients and staff as they contemplate a long afternoon in the dayroom of a psychiatric hospital with a mix of patients that includes the violent and aggressive with the weak and vulnerable.

They have observed heavily drugged patients tied to their beds, left in hospital hallways, and soaked in their own urine. Psychiatric patients and mentally retarded residents were regularly observed with cuts and bruises and one resident was observed bloodying himself during a seclusion period in full view of ward personnel.

There are indications that similar or more severe acts of violence, including beatings of patients and residents by others including staff exist as an open secret of institutional life.

I'll not point the finger of blame solely at ward personnel. That is too easy. These workers have some of the toughest jobs and the most inadequate tools, including training, to do the jobs. Indeed, the levels tolerated at many facilities subjects the employees themselves to a variety of injuries and even death.

But let's be clear about the responsibilities that a State assumes when it institutionalizes the mentally disabled, especially those with the most severe psychiatric disorders. These responsibilities must include providing conditions that meet basic human and constitutional rights.

Some States have exemplary systems for ensuring these rights. Others have nothing but lip service.

Let us also be clear about the Federal Government's responsibilities to the institutionalized. When we passed the Civil Rights of Institutionalized Persons Act in 1980 we expected that these persons would, at last, live and be helped in conditions that meet tests of constitutional certainty and human decency. When we provided for Federal audits of institutional care as part of Medicaid funding, we expected that Federal tax money would be linked directly to quality care. However, neither the U.S. Justice Department nor the Department of Health and Human Services has lived up to these expectations.

Instead, there is a well founded belief in some States that physical health and safety and the broader issues of training and rehabilitation are factors of the bottom line of budgets, more than factors of basic human rights.

Instead of tough Federal action to correct serious and potentially deadly institutional conditions, we are left with isolated media reports and limited State and congressional research, including this report by my staff.

Instead of educating the public, opening the wards to review and achieving proper care in whatever setting, the self-serving actions of many States and full retreat of the Federal agencies has stifled the screams and abandoned the ill. This ensures that our successors will be here in five years, ten years and beyond listening to the same tragedies that patients, residents and staff are now living.

Hearings by themselves won't tear down any walls. But the people who are here to testify, possibly at the risk of their jobs, and the institutionalized people who can't be here, at the constant risk of their lives, demand that we try.

Senator WEICKER. First of all, in terms of the origins of this hearing, in November 1983 I had Bradford Reynolds of the Justice Department before my subcommittee. I asked the following question: If one of these person's life could be snuffed out in the next hour and you know about it, do you have the power to go in there and make sure that life will not be snuffed out? Do you have the authority right now to save that life?

Mr. Reynolds gave the following answer: "I think that if you know in advance that somebody is going to—your situation is if you know in advance that somebody is going to snuff out a life in the next hour I would"—and then there was a 30 second pause—"I am not sure what; I would have to look into that and whether the Federal Government is in a position to go in in advance on that." It was the response to that question and the obvious jeopardy that existed for retarded and mentally ill citizens that prompted me to request of staff a further investigation.

I have worked with staff over the past months, but I read their written report for the first time last weekend. I want to tell you my reaction, and I think it is important because the purpose of these hearings is to alert the Nation not just a subcommittee or the Senate. And I think it should be pointed out that I viewed this report as somebody who has worked now with the handicapped and the retarded for many years.

But after I finished reading the report I have to say to you that I was not shocked. The writing of the report itself by my staff was superb, and we shall include it in the printed record as the appendix to these hearings. The report also enumerated the fact that patients were maltreated and abused.

But I said to myself that this is just not graphic enough to carry a message to the American people, much less to this Senator. I went home and I thought about it, and I kept on thinking about it, and do you know what the problem is? This report is just about as graphic as you would want if it were a report issued by NIH, or if it were a report issued about your local hospital and those patients who are there for the treatment of cancer, or a home for the treatment of Alzheimer's disease, or those suffering from AIDS or the myriad of other diseases that affect all of us.

If 1/100th of this Senate report ever related to these hospitals and institutions which serve us and our family members we would all be up on the ceiling. But let us face that, as a nation, and I will point the finger at myself, we do not include treatment of the mentally ill and the mentally retarded in that category. Rather, we view their conditions closer to criminality rather than to illness or disease.

When we read about these institutions, we relate them more to a prison than to a hospital. This is not a hearing on the criminally insane. This is a hearing on human beings, young and old, who suffer just as much as a cancer patient, or somebody from heart disease, Alzheimer's, AIDS, cerebral palsy, or multiple sclerosis; it is exactly the same, no different.

And yet I think that in order to make the point, what do you have to have, 600 people die in a mental institution, or 600 raped—will that make the point? Why is that necessary? One is sufficient in terms of any other illness or any other institution. This Senate report says it all. It is not the report that needs to be changed; it is our attitudes, as I said, mine included. It is not a finger pointing exercise. It is our shame, our shame.

For every time we hear a story or hear somebody speak I just hope the whole Nation adjusts its mindset, adjusts the national mindset that this person is just the same as someone who suffers from those other diseases or illnesses, and who would certainly evoke our love and our sympathy.

I also have to say to all of you I had reservations about these hearings to the extent that hearings have been held in the past, and there followed a great flurry of activity, and then nothing else happened. And in some ways families and patients are left off worse than before.

That is not the intention of these hearings. Already staff has prepared the necessary legislation to plug up these loopholes, and believe me, I intend to do all I can to see that it is enacted in this Congress.

Lastly, there has been somewhat less than full cooperation by certain government entities, both Federal and State. There has been complaining that either certain witnesses should not be heard or that there ought to be rebuttal testimony. And the answer is for the time being that this is a chance for those who need our special care in this Nation to be heard. It is their chance. The Government has 365 days a year; it has had years. It has had the stage to itself.

So, yes, the first 3 days of these hearings will focus on those who have been left in the backwaters of our conscience. I will announce this morning the opportunity for anybody who cares to make a statement, that it can be accepted at any time for the record, and at the end of the Wednesday hearings there will be time for additional testimony by those who feel that they have a new matter for consideration by the committee.

Are there any further opening statements to be made this morning? Senator Simon? I would like to introduce the new members of the subcommittee, all of whom are Democrats: Senator Kerry, who is the new ranking member, Senator Simon, who is with us here, Senator Kennedy, and also my good colleague, the ranking member of the Appropriations Subcommittee, Senator Proxmire. Senator Proxmire, Senator Simon, welcome, and I look forward to any opening statements and then we will proceed to the first witness.

Senator **SIMON**. Just briefly, Mr. Chairman; first of all, as a Member of the House I was interested in this whole general area. I think the real test of whether we are a civilized society is not how we pander to the whims of the rich and the powerful; it is how we help people who really need help in our society. And your leadership in this area is widely known and respected, and I am pleased to be associated with you on this subcommittee.

I join in your concern about the response of some of the agencies of the Federal Government, particularly the Justice Department in this area. I think holding these hearings and then making sure we follow through is extremely important.

I particularly appreciate your staff actually going into institutions and checking out what is happening. I think it is extremely important and I look forward to working with you.

Senator **WEICKER**. Thank you, Senator Simon. Senator Proxmire.

Senator **PROXMIRE**. Senator Weicker, I do not have an opening statement. I would like to congratulate you, however, and to tell those of you who are testifying today that you could not be in better hands than Lowell Weicker. I have worked with him now for several years, and he is as compassionate and realistic and effective a Senator as I know. And, of course, Paul Simon is a man I have admired greatly in the House. It is marvelous to have him in the Senate. Except for this Senator it is an all star panel of Senators. Two out of three is not bad.

Senator **WEICKER**. It is three out of three. Thank you very much. We now move to our first witnesses. We have a panel. On that panel are Mr. and Mrs. Harold Cockerham and their son Chris from Fort Worth, TX. Mr. and Mrs. Cockerham and Chris, hello and welcome to the committee. Mr. Wilbur Savidge and his son Jonathan. Mr. Savidge, it is nice to have you with us. And David Ferleger, Esq., attorney from Philadelphia. Mr. Ferleger, it is nice to have you with us.

I think, as I understand it, Mr. Ferleger, you are connected with both sets of witnesses here. Why do you not proceed in the way that you would like to here in terms of your testimony before the committee.

Mr. **Ferleger**. I think we will have Mr. Cockerham testify first and then Mr. Savidge and the lawyer will go last.

Senator **Weicker**. Fine. Mr. Cockerham, welcome.

STATEMENTS OF MR. AND MRS. HAROLD COCKERHAM AND SON CHRIS, FORT WORTH, TX; WILBUR SAVIDGE AND SON JONATHAN, HURST, TX; AND DAVID FERLEGER, ESQ., PHILADELPHIA, PA

Mr. **Cockerham**. As of February of this last year my wife was called from the Fort Worth State institution that my son had been bruised but he was in good shape and there was no hematoma. That evening my wife and I went out to the home to check Chris, and as we walked in his head was scarred up. He had a black eye. I removed his shirt and he was lacerated and bruised from his neckline to his buttocks.

I asked to be excused from the building and I went out and got my camera, brought the camera back in, and started taking pictures. The attendant left immediately and brought back the assistant superintendent of the home. He indicated to me that he already had pictures and there was an investigation going on.

I told him I had my pictures, too, and to get his clothing because I was taking him out. I kept asking Chris what had happened, and he was very embarrassed about the thing and he would just hold his head down.

After coaxing him for awhile he did indicate that there was a person that had hit him. I asked him to point out where it happened and we went through numerous locked doors back to his bedroom and he pointed to his bed and started crying.

They indicated that they would go through a thorough investigation and let me know what happened. I took them at their word. I could not take Chris home, but I took him to my mother's house because my daughter would be so distraught after seeing what had happened.

He stayed at my mother's house for 2 days; he would not rest for that period of time. He never did go to sleep for 48 hours. I did not realize that I should have called the police at the time and my mother was so upset she did call the Fort Worth Police Department.

They came out and made a report and the home never did call the police department. After 2 weeks they indicated that they did not know what had happened and could not come up with enough information to give us anything on it, and I said, well, I will proceed from this point. I got deeply involved with the police department and we got two indictments on two of the attendants that were supposed to be watching him that night. They have not come to trial yet.

During this period of time the superintendent never once wrote a letter to us, came to us and apologized, told us he was sorry for what happened, nothing. This is very disturbing. I feel the State institutions right now are warehousing individuals and not caring for them in a caring manner.

Hopefully, things that happened to Chris and Jonathan will not happen to thousands of other kids if we get the right laws passed. Hopefully, we can.

Senator **Simon**. Mr. Chairman, if I may ask, how old was Chris at the time this happened?

Mr. **Cockerham**. Twelve years old.

Mr. **Ferleger**. I do not know if you can see them here. Some of the other Senators besides Senator Weicker may not have seen the photographs that were taken as of the time the incident happened. Maybe I can pass them around to the Senators.

Senator **Weicker**. Will the staff bring those photographs to the chairman, please.

Mr. **Cockerham**. I would like to bring up one point that irritates my wife and I to death. At this point the ladies that were indicted for this act are still being paid by the State. There was a joke going around the State facility that you could beat up a child and get a year off with pay. That hurts.

[The prepared statement of Mr. and Mrs. Cockerham follows:]

PREPARED STATEMENT OF MR. AND MRS. HAROLD COCKERHAM

Testimony

Honorable Lowell Weicker, Jr., Chairman

Sub-Committee on the Handicapped

and the Appropriations Sub-Committees on Labor, Health, and Human Services and Education

Regarding: "Care and Advocacy for the Mentally and Disabled Persons in Institutions"

This information is about the severe abuse that was inflicted upon our son, Christopher, by staff personell at Ft. Worth State School, where Chris was residing at that time.

On February 27, 1984, I received a phone call at work from Vee Anderson, our appointed social worker (at that time; she has since resigned). She told me that the morning shift had discovered bruises on Chris that morning and that they did not know how or when, they had occurred. She said that the doctor on staff had checked Chris and that he was all right, alert, and had no sign of hematoma. Vee said she just wanted to let us know. I asked her if she had asked Chris who did it. She said all he would do was put his head down, not look at her, and would not answer.

I cannot begin to describe how upset and stunned I was. I contacted my husband, We both met at home and then went, (unannounced), to see Chris. Vee brought him into the day room. He had a black eye, bruises on the right side of his head and face, and bruises on both sides of his neck. At that point, my husband asked for the outside door to be unlocked so he could go outside. He went to our car and returned with our camera. We began to undress Chris and found him covered with bruises and whelps on his back, neck, and entire buttock area. He had been severely beaten! When we began taking the photographs, Vee left and shortly returned with an Assistant Superintendent by the name of Darrell Logan. We asked Chris who had hurt him, but all he would do was drop his head. After a long time he finally told us the name of the woman. At that point I asked Vee who that was and she told us it was an employee. We asked Mr. Logan how something like this could happen and if he knew who had done it. He told us that they had been checking all day and had not been able to find out anything. He assured us there would be an investigation and that they would let us know when they found out anything.

We left, taking Chris with us. He did not go to sleep for over forty-eight hours, and then he did not rest well for having nightmares, and being very restless and nervous. When he was awake he was very hyperactive. He is now resting a little better, however, he is not completely free from his anxieties during his sleep. Chris also has suffered a hearing loss. When we noticed it, we asked that Ft. Worth State School do a hearing test on him. They did one and told us his hearing was fine and that he had no problem. We then took him to an ear specialist and audiologist and had a test done. They found that he has a severe hearing loss. They couldn't believe the results of the test done by Ft. Worth State School!

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We believed them, when they told us they were investigating the matter, but after two weeks, they told us they had completed the investigation and had not found out anything. That was it! They were finished and were going to leave it at that. We had been so naive. We really had believed they would do what was right. Needless to say, we have learned a great deal from all of this.

We contacted the police department. They ended up assigning our case to a special task force, who turned over their findings to the District Attorney's office and they turned it over to a Grand Jury. The Grand Jury brought indictments against the two women (one was the same one Chris told us beat him) and they were arrested and placed in jail, only to be released the same night. The Union is backing them. They had them released and are handling all of their legal fees. The two women returned to work the next day. My husband called the Superintendent of Ft. Worth State School, Mr. Mel Hughes, and after much discussion, Mr. Hughes agreed to suspend them until after their trial. We later learned they were suspended with pay! And, may I add, they are still on paid leave!

After we decided to have an investigation made by the police department and get involved in seeing that something be done, and after it became public, our telephone never quit ringing. The calls were from parents of children at Ft. Worth State School. They had all had experiences but did not know what to do about them. Some just asked for advice and some just wanted to let us know about their experiences. One call was from a lady who had been given our number by a mutual friend. The mother was upset because when she went to visit her daughter she discovered the daughter's front teeth were missing! When she inquired as to how it occurred, she was told not to worry about it. She couldn't believe it. She took her daughter to a private dentist. He first told her he thought the girl's jaw was broken, but later said it wasn't. The mother was so upset. She wanted us to give her advice. We really think she was afraid to do anything because she said she was scared they would dismiss her daughter if she caused too much trouble. She called us quite a few times. Later, upon hearing the news report on our case being turned over to a Grand Jury, she called and said her husband told her they should call the District Attorney's office and see if they could be of any help. Anyway, we are not sure whether or not they ever contacted them. We feel she was very intimidated.

Another call we received was from a girl who has a brother residing at Ft. Worth State School. She worked in the same office with a good friend of ours. He told her about what happened to us and she just wanted to meet us and talk to us. She came over to our house and talked to us. She told us so many things that happened to her brother. There are too many to tell now, but there is one incident we think you should hear about. Only a few days after she visited us she received a call from her brother. He told her he was hurt. She came by and borrowed our camera, (her camera was broken), and she went to get him. He had been cut up a lot. He told her who did it to him. He said the attendant did it after he refused to have

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sex with the attendant. Another time, not very long after that, he called her again and told her he was hurt. She went to get him. There happened to be a news reporter standing outside Ft. Worth State School giving a report in regards to our case. While they were filming, she came out with her brother. His nose had been broken! It was perfect timing. They got him on film too.

Another woman who had a child at Ft. Worth State School is the secretary of a friend of ours. One night our friend called us and told us she had called him late the night before and was crying and upset! She told him Ft. Worth State School had called her and told her that her son was dead! She had just had him home a few days earlier and he had been fine. She wanted our friend to be sure and let us know about it. We told her to be sure and tell them to have an autopsy and complete toxicology report done. She is still having problems with Ft. Worth State School.

Another friend called and told us about a friend of hers whose husband had done some construction work at Ft. Worth State School and she had overheard her husband and some of the other men talking one night about how terrible it was out there and about the awful things they saw the employees doing to the clients. They couldn't believe what was going on. She told the mutual friend and the friend called us. So we called and talked with the woman. She told me about it. We asked her if she would have her husband call us. Later she called and told us that she was very sorry, but that when she told her husband about talking with us, he got very angry with her for telling anyone.

He told her he could loose his job and for her to keep quite.

Another acquaintance of my sister, told us she had worked at one of the I.C.F.M.R. facilities in Ft. Worth (associated with Ft. Worth State School) a while back and the abuse, neglect, and sexual activities that occurred there were awful!

We could not believe how many people were victims and yet nothing was done. The more we became involved, the more we kept finding out!

Something very important you may be interested to know is, that we have never met or spoken to Mr. Hughes, the Superintendent of Ft. Worth State School. He has yet to this day, tried to get in touch with us in person, by phone, or mail, to express his condolences to us about the incident of abuse to our son. The only time we have spoken with him was the time my husband called him complaining about the women being allowed to return to work after their release from jail, and that was the only thing that was discussed. I think that says an awful lot!

Had we not pursued it, we both know this entire matter would have been covered up, just as all of the other awful things that are occurring there continuously, are covered up.

Our son is now residing in a small-group residential home and is attending public school in Arlington, Texas. He is doing very well in school. It is so sad that it took all of this to occur before he was placed somewhere he should have been all along. We would like to express our experiences and findings of small-group residential facilities versus institutions. Our personal experiences have been positive proof that it is the best alternative. Our son was finally given the opportunity to attend public schools after a year of residing at Ft. Worth State School without schooling. However, he was later expelled from school. We were told he was expelled because he was unmanageable. We believe he was a victim of his enviornment. After he was place in the small-group home he began attending public school again and we have been repeatedly told how well he is doing in school and with no problems. We both have very strong feelings about how much better the care for children in the small-group homes is, and about them being a superior alternative to institutions.

So much has been going on and is still going on in the institutions. Some changes have to be made! These children cannot help themselves. Some of them have no one. Some are wards of the state, some are abandoned, etc, and they have rights just like anyone else!

It is very difficult to describe how we felt when this happened. The first thing we felt was shock. Next we were just numb. We felt so violated. Then we were hurt. As time went on, we became bitter. We are trying vwery hard to direct that bitterness in a positive way. Hopefully, this testimony will bring about some desperately needed, positive changes.

Respectfully submitted,
Mrs. Harold Cockerham
Mr. & Mrs. Harold Cockerham

Senator WEICKER. I am going to have questions to ask of Mr. Cockerham, but I thought you would like to, counselor, present the entire story and then we can get to the questions from the committee.

Mr. SAVIDGE. Senator, on behalf of Jonathan and his mother and my daughter here we appreciate the opportunity to be here today.

Citizen Jonathan Savidge is 12 years old and currently confined by the Texas Department of Mental Health and Mental Retardation in a large State institution, the Fort Worth State School. The Fort Worth State School is far removed from the mainstream of community living. It is located in a region on the South Side of Fort Worth. It exists because of the failure of the Texas Department of Mental Health and Mental Retardation to provide alternatives such as foster care or community homes.

Jonathan was born at Harris Hospital in Fort Worth, TX, and appeared normal at birth. But at the age of 6 days he suffered two respiratory arrests at home. His mental deficiencies were first suspected at the age of 3 or 4 months. By the age of 7 Jonathan was still unable to walk unattended and underwent an Achilles tendon operation in November 1979.

We sought help from the Texas Department of Mental Health and Mental Retardation in 1979. After numerous conferences and only after accepting the fact that placement at the Fort Worth State School was the only alternative offered, Jonathan was placed in the school in September 1980.

Jonathan requires a highly structured environment, providing physical, occupational, speech, and language therapy as well as specialized services that are impossible for us to provide at home. Acquiring self-help skills such as walking, toileting, dressing, control of hyperactivity would have allowed Jonathan to live at home again. The hope of having Jonathan acquire these skills and return home is what we felt the Fort Worth State School offered us.

In the year prior to Jonathan's placement at Fort Worth he was taught at home by our local school district. He could use his fingers to make a pointer; he could dial the telephone. He could turn off and on a cassette player. He could say "mama," "dada," "bye-bye," and "mine." And at the time he was placed in the Fort Worth State School, according to the placement programming conference, September 30, 1980, it stated that Jonathan is easy going, happy, his strengths being relatively free of seizure activity and no major health problems. He wears braces and can ambulate to some extent in a walker with the aid of braces. Jonathan is able to propel his wheelchair independently.

Jonathan left a loving home environment to live in a stark, void, filthy institution. This situation was carefully hidden from us during the admission process. Today Jonathan is totally nonambulatory, has lost the use of his right arm and leg, has generally lost many of the skills he possessed before placement at the Fort Worth State School.

We always bring Jonathan home on weekends and holidays. In the first few weeks after we placed him we saw him playing on the floor in the dormitory chewing on a urine soaked stocking that belonged to another client. We saw clients on the floor crawling through feces. And I saw staff employees sitting on chairs carrying on conversations and would do nothing about the problem.

Every weekend when we bring Jonathan home, almost every weekend we will find some new bruise, scrape or cut of some kind.

After he had been there approximately 3 months Jonathan developed a staphylococcal bacteria infection that manifested itself in boils. That was the first indication that I knew of it. Over a period of the holiday weekend, 1980, the Christmas season, we noticed these boils enlarging. They treated those boils by putting a liquid medication on them with a Band-Aid. Jonathan would remove those Band-Aids within minutes after they were on him even though they were on his back and on his shoulder blades.

We were a little upset about this because we realized Jonathan is the fifth of children; I have been a professional parent, I think, for 30-odd years now. This is my oldest child here, Billy. We have learned something about the care and treatment of children at home. And they were not treating these boils carefully and they kept enlarging.

We notified the staff workers. We talked with the people at the building. We questioned the inappropriateness of applying medication this way. We felt that the medical staff was competent and used to handling children like Jonathan.

In December of 1981 we discovered the boils, and three times during that month we had to return Jonathan to the home on a weekend because he was running a temperature. The doctors would look at him or so we were told. We found many times only a nurse would examine him. The situation reached its climax on January 13, 1981.

Senator, I would like to walk you through the terrible ordeal we experienced that night in 1981. At 10:30 p.m. in the evening we received a phone call from a doctor at the Fort Worth State School. This doctor had extremely poor command of the English language, a very difficult person to understand.

We were told that Jonathan was very sick and was having seizures. We were asked for the name and phone number of our personal physician. The conversation was very unclear. We could not understand if the doctor wanted us to come to the school or if Jonathan was going to be taken to a hospital. The doctor hung up before we could find out what was wrong and what we should do.

We immediately called back and a nurse informed us that the doctor was busy and hung up. Of course, we were very angry, very upset, and we promptly went to the school, about a 20- to 30-minute ride from where we live.

Upon arrival at the medical building we met with a doctor. She was obviously upset and during our discussion implied that Jonathan was having some kind of a heart problem. It was learned later that this doctor had even discussed the problem with a cardiologist consultant. The doctor seemed very confused and asked my opinion about whether Jonathan should be taken to the community hospital where his heart records were, Tarrant County John Peter Smith Hospital, or if our personal physician should treat him.

When we examined him Jonathan was unconscious and on an IV. The doctor discussed the problem with our personal physician who told this girl doctor that if the problem was not heart related she would be willing to treat him at the local hospital where she practices.

We were left alone with Jonathan and he was having more seizures. This continued for quite some time, and finally they decided that the doctor should go see our family pediatrician. They did not offer any help or assistance. He was removed from the IV, shoved through the door on a cold winter night in a nightshirt without any covering.

I asked if someone was going to go with us; they said, no, we cannot leave the building. So we took Jonathan by ourselves on about a 45-minute ride never knowing if he would go into convulsions on the trip or not. In the following days he had a lemon sized abscess, a pocket of pus removed from his right rib cage.

He recovered from that operation and a few days later went into convulsions. And we had a CAT scan performed and found out he had a walnut sized abscess in the brain. And over the next 3 or 4 months he had a brain operation that has left him paralyzed on his right side. He has lost the usage of his right arm and right leg.

Since that time, by being confined to an inappropriate wheelchair, he has developed scoliosis, which we were never informed of.

I think Jonathan has paid a terrible price to spend the time he has in an institution run by paid employees that we expect a lot more from. Thank you.

[The prepared statement of Mr. Savidge follows:]

Prepared Statement of Wilbur M. Savidge

February 27, 1985

Honorable Lowell Weicker, Jr.
Chairman
Subcommittee on the Handicapped
Committee on Labor and Human Resources
United States Senate
Washington, DC 20510

Dear Senator Weicker:

I greatly appreciate the opportunity to participate in the hearing to be conducted by the Committee on March 11, 1985.

Following is a snyopsis of the care and treatment of Jonathan Savidge at the Fort Worth State School:

Citizen Jonathan Savidge is twelve years old and currently is involuntarily confined by the Texas Department of Mental Health and Mental Retardation (TDMHMR), in a large state institution, the Fort Worth State School.

The Fort Worth State School, far removed from the mainstream of community living, is located in a remote region on the South side of Fort Worth. It exists because of the failure of TDMHMR to develop or expand alternatives such as foster care programs or small community homes.

Jonathan was born at Harris Hospital in Fort Worth, Texas. He appeared normal at birth. At the age of six days, he suffered two respiratory arrests at home. His mental deficiency was first suspected at the age of three to four months because of a delay in the development of his motor skills. By the age of seven, Jonathan was still unable to walk and underwent a Achilles' tendon operation in November of 1979.

We sought help from TDMHMR in 1979. After numerous conferences and only after accepting the fact that placement at the Fort Worth State School was the only alternative offered by TDMHMR, Jonathan was placed at the Fort Worth School on September 9, 1980.

Jonathan requires a highly structured environment providing physical, occupational, speech and language therapy as well as specialized services we could not provide at home. Acquiring such self-help skills as walking, toileting, dressing and control of hyperactivity would have allowed Jonathan to live at home again. The hope of having Jonathan acquire these skills and return home was what we felt the Fort Worth State School offered us.

The year prior to Jonathan's placement at the Fort Worth State School, he was taught at home by our local school district's Home-bound Teacher Program. The instructor found Jonathan teachable. He would turn a book right side up and correctly pat objects when requested. He would make a "pointer" with his finger and "dial" a telephone and appropriately turn on and off a cassette player. While limited in vocal skills, he could say "Mama", "Dada", "bye-bye", "baby" and "mine."

The following excerpt is a quote from the Fort Worth State School's "Placement Program Planing Conference Summary and Diagnostic Finding, Fort Worth State School, Dated September 30, 1980":

> "Jonathan is happy and easy-going. Jonathan's strengths lie in his being relatively free of seizure activity and no major health problem. He wears braces and can ambulate to some extent in a walker with the aide of braces. Jonathan is able to propel his wheelchair independently."

Jonathan left a loving home environment to live in a stark, void, filthy institution. This situation was carefully hidden from us during the admission process. Today Jonathan is totally non-ambulatory, has lost the use of his right arm and leg, and has generally lost many skills he possessed before placement at the Fort Worth State School. We always bring Jonathan home on weekends and on holidays. In the first weeks after placement, we saw him playing on the floor of his dormitory chewing on another client's urine-soaked stocking. Other clients in the area were playing in each others feces. The floor was always filthy and, the direct care employees never seemed interested in cleaning up the filth or the clients.

Every weekend when we brought him home, we noticed that he had new bruises and within ninety days of placement, Jonathan contracted a staphylococcal infection. This life threatening condition was known by the school administration. However, no effort was made to correct the problem nor were procedures implemented to protect clients, like Jonathan, who were known to be highly susceptible to infections. During the following week, Jonathan was denied necessary medical attention and was subjected to treatment which certainly could not be accepted as professional medical practice.

Jonathan's social worker notified us on December 18, 1980, that Jonathan had broken out with three boils. On the following weekends, we continued the prescribed treatment, a liquid covered with a Band-Aide that Jonathan could promptly remove. We corrected the problem of his removing the Band-Aides by dressing him in bib overalls. We questioned the unappropriateness of applying medication in this way. However, at the time, we felt that the medical staff at the Fort Worth State School were competent and were accustomed to handling children like Jonathan.

By January of 1981, we discovered that the boils were enlarging and that Jonathan had developed a body rash and a temperature. Early that same month, on three occasions, we returned Jonathan to the school medical building because he was running a high temperature. On two of those occasions, we were told that a doctor would see him that day (Sunday) when in fact he was only examined by a nurse. This situation reached its climax on January 13, 1981.

Let us walk you through the terrible ordeal we experienced the night of January 13, 1981. At 10:30 p.m., we received a call from a doctor at the Fort Worth State School. This person had an extremely poor command of the English language and we found it difficult to understand her. We were told by this doctor that Jonathan was very sick and that he was having seizures. We were asked for the name and phone number of our personal physician. The conversation was very unclear and we could not understand if the doctor wanted us to come to the school or, if Jonathan was going to be taken to a hospital. The doctor hung up before we could find out what was wrong or what was going to happen. We immediately called back but, a nurse informed us the doctor was very busy and hung up. We were exceedingly angry and promptly went to the school (a thirty minute ride).

Upon arrival at the medical building, we met with the doctor. The doctor was obviously upset during our discussion and implied that Jonathan was having some kind of a heart problem. It was later learned that the doctor had even discussed the situation with a cardiologist consultant. The doctor seemed very confused and asked our opinion about whether Jonathan should be taken to the county hospital that had his heart records or, if we thought our personal physician should treat him. When we examined him, Jonathan was unconscious and on an IV. The doctor had discussed the problem with our personal physician who told the school's doctor that if the problem was not heart related, she would be willing to treat him at the local hospital where she practiced.

We were left alone with Jonathan when he began having more seizures. The doctor and nurses then rushed to his room. Jonathan's doctor could not ascertain what was wrong but it was obvious to us that Jonathan was very sick and needed immediate hospital treatment. The Fort Worth State School medical building is not an accredited hospital. In fact, at a later time, the Tarrant County Medical Examiner publicly stated that the school's facility is far below ethical standards to provide proper care for seriously ill clients.

We went to Jonathan's room and, upon seeing his condition, demanded that he be transported to one of the two hospitals previously suggested. The doctor seemed uncertain and unable to make a decision. We finally told the doctor to call an ambulance and have him taken to our local hospital and call our personal physician. We were then informed that the Fort Worth State School could not provide transportation to any hospital as they did not have a contract with an ambulance carrier in the area.

At this particular time, we still did not know the seriousness of Jonathan's illness. However, we did believe the problem was not heart related. Since it was obvious that the school's doctor was unable to handle the situation, we felt our physician should see him. We told the school's doctor that, since the school could not obtain an ambulance to transport Jonathan to a hospital, we would take him in our van. We then instructed her to call ahead and make arrangements for admission and get Jonathan ready for the trip.

All of these events took place during a period of forty-five, nightmarish, utterly confusing minutes. We brought the van around to the medical building door and watched in dismay as the nurse brought Jonathan to us. He had been taken off the

IV and placed in his wheelchair. One nurse was holding him upright while the other pushed the chair. Jonathan was dressed only in a hospital dressing gown, without the benefit of a blanket or other covering, despite the fact that it was January, cold, and raining outside. We were offered no assistance in transporting him to the hospital. We wrapped Jonathan in a blanket that we had with us and placed him in the van. We asked if the doctor or a nurse would accompany us to the hospital and were told: "No they could not leave the building."

The trip to the hospital took another forty-five minutes and we lived in fear during the entire trip that Jonathan would go into convulsions again. Jonathan's condition was very unstable and within a minute of reaching the hospital, he had a static seizure. Our personal physician spent many hours working on Jonathan. Two days later, a lemon-sized abscess was removed from his rib cage. A few days after this operation, he began having severe seizures and our physician transferred him to the county hospital for a CAT scan. This scan revealed a walnut-sized abscess on his brain which was removed several weeks later. The end result of this incident is that Jonathan is now paralyzed on the right side. Today, Jonathan is totally non-ambulatory with no hope of ever walking again. His present condition greatly diminishes his chances for ever living at home. Despite five years of paper documented programs at the Fort Worth State School, he is not toilet trained and has lost physical, speech, mobility and communication skills. Jonathan has suffered further harm by being confined in his wheelchair which is unappropriately adapted to his needs and is often left unrepaired and is always filthy.

Jonathan has developed scoliosis, a severe curvature of the spine, that will probably require surgery to prevent the condition from becoming a life-threatening problem. The Fort Worth State School knew the scoliosis was developing and took no appropriate action to prevent its further development or inform us of the situation. We discovered the problem when an independent consultant examined the school's records. On January 16th of this year, Jonathan underwent open heart surgery to correct a serious heart deformity. Again, the school knew of the developing problem and totally failed to inform us. Again we only discovered this problem when we decided to investigate a related medical treatment the school doctor would not explain.

After consulting with Jonathan's cardiologist in early December, surgery was scheduled for January 16. The Fort Worth State School doctors were informed of this decision and were asked to begin admittance procedures for him at Fort Worth Children's Hospital. They failed to do this, and we learned that the school, without informing us, had scheduled him for an appointment in Galveston, Texas, hundreds of miles away. The Galveston hospital was told by the doctors at the Fort Worth State School that the parents wanted a second opinion! This particular hospital was contacted by the school only because it performs operations for state institutions on a no charge basis! No one at the school to this day has ever discussed this most recent operation with us. We have had to make all the arrangements and were forced to bring Jonathan's attorney into the problem to resolve the school's unwillingness to agree to pay his medical bills despite the fact that Jonathan is receiving Medicade.

It is apparent that the Fort Worth State School cannot appropriately meet even the simplest of daily needs or problems. Jonathan was kept in the same shoes for four years, despite the fact that he is growing and gaining weight. Again, we had to fight the school just to get the proper size shoes for his feet!

The Fort Worth State School's own records indicate that Jonathan has been injured 124 times since his admission. However, we were informed of only 25 such incidents. Jonathan has been routinely punished by having his wheelchair placed in a corner, wheels locked, and large pieces of furniture wedged against the chair forcing him to sit and stare at the wall. He is unable to play or see others in the room.

The school is understaffed and we have often seen one direct care worker trying to handle up to twenty-seven clients scattered throughout two bedrooms, a bathroom, a hall and a playroom. The dormitory where Jonathan lives smells of urine and feces. The floor is often filthy and on second and third shifts, and on weekends and holidays, approximately eight percent of the total number of employees are on duty (these are times when most abuses and deaths occur and also when a doctor is not on campus). In a meeting covered by a newspaper reporter several years ago, a doctor at the Fort Worth State School said that they had "the bottom of the barrel," with reference to the clients at the school.

We have no alternative. Jonathan must endure the system even though his life is constantly threatened by poor care and treatment. We would ask why does the Federal government allow these atrocities to go unchecked? Who can we turn to when the Justice Department refuses to investigate abuse and death in state institutions? We have been fortunate to receive financial support in our litigation from the Brums Foundation, an organization established by the family of Mark Jones who tragically died at the Fort Worth State School in 1980. What about less fortunate parents, those without the financial means necessary to support a federal lawsuit? The State of Texas has, in Jonathan's case, displayed a callous, uncaring attitude toward all handicapped, retarded citizens entrusted into their care. The victims of this system must have our concern and understanding for they, like Jonathan, cannot speak for themselves. Is our government a government of all the people? Or, are retarded and handicapped citizens of this country the "bottom of the barrel"?

Respectfully submitted,

Wilbur M. Savidge

WMS/srh

Mr. **Ferleger**. Senator Weicker and the other Senators who are here, it is both an honor and almost a disgrace for us to have to be here today and to have to tell the Senate of not only what is happening around the country in institutions but to try to suggest some remedies because one would have thought that the 50 States of the United States would long ago have remedied the abuse that goes on every day in institutions.

Institutionalization has a dramatic and even deadly effect on people who live in them. The horrors of institutions extend from death to physical abuse and other kinds of maltreatment, and what is worse, in my opinion, is the unnecessary confinement of thousands, tens of thousands of people in institutions for the retarded in the United States.

What I would like to do is talk about several particular instances and then suggest some remedies for legislative action by the Congress. My role here is both as an attorney who has practiced my entire legal career in representing people with disabilities; I am the lawyer that filed the *Pennhurst* case that I argued several times before the U.S. Supreme Court. I teach at NYU's law school, and I represent people around the country in the disability area not because I like flying around in airplanes, but because people in Texas and other places have very few legal resources to turn to when they need help in this area.

One year ago in Texas, hospital officials intentionally caused the death of Gladys Piland who was a 49-year-old resident of Fort Worth State School. She became mysteriously ill, was transferred to a hospital 3 days later, and 5 days after that, although according to the medical records, the doctors "did not know what was wrong with her," she was taken off a respirator. The records say, "On March 20, 1984 at 11:30 a.m. she was expired."

And, you know, Senators, that if it was you or I and we were in a coma for a couple of days nobody would have killed us. The fact is she was an inmate of an institution and her life was expendable.

Kenneth Gene Johnson was 4 years old when he died at the Denton Development Center. The Denton Development Center in Texas is run by a corporation that is owned by ARA Services, one of the largest services conglomerates in the United States. Kenneth's mother is here today sitting behind me to my right.

Kenneth Johnson was left unattended in a wheelchair, had a seizure, and choked to death in his wheelchair straps, the wrong straps. He was tied in the wrong way, and when he died in October 1980 he was, as I have seen myself at the Denton Development Center, down the hall in clear view of the nurses station.

A grand jury returned an indictment of the corporation for manslaughter, but the district attorney decided along with the State not to pursue it.

At the New Lisbon Developmental Center in New Jersey a resident named A.F. was killed also. Now, he was not killed by the staff exactly, although I think anyone in this room would hold the staff responsible. Another resident named J.S. in his thirties had threatened repeatedly in prior weeks to kill A.F., had even beaten him up a few times. And finally on September 10, 1983, according to the State's own investigation and according to the newspaper reports at the time—but I have seen the State's report—on that date

J.S. beat to death A.F. with the staff of the institution standing by watching.

Jonathan Savidge, whom you have just heard about from his father, suffered a near fatal brain infection after crawling through the human filth that permeated his ward.

And I want to say that in the case that arose from that situation, which is still in court, the superintendent of Fort Worth State School, Mel Hughes, testified that he himself has seen the puddles of urine on the wards of Fort Worth State School. Fort Worth State School is a new facility opened in the early 1970's, but newness has nothing to do with providing decent care.

The situation of Chris Cockerham, which you heard described a moment ago by his father, is one that within 2 weeks of the incident, Senator Weicker, I referred that to my friends at the Justice Department here in Washington. I wrote a letter; I sent the pictures, the same pictures you saw, asked the Justice Department to intervene in the class action that is pending in Texas, and to do something about the situation of Chris Cockerham and other people being abused.

I filed a motion with the court seeing if the court would force them into the case under the Civil Rights of Institutionalized Persons Act. The Justice Department did not act. They asked me for more information a couple months later. I gave them more. I gave them all the abuse reports from Fort Worth State School, and they said it was still not enough of a basis for them to even begin to investigate on their own.

And finally I got a letter from them 6 months ago, about 6 months after the incident, saying that they would not get involved.

Senator **Weicker**. That was the response to this from the Justice Department of the United States.

Mr. **Ferleger**. They refused to respond. The response was "no thank you." I must say we had their help in the *Pennhurst* case beginning in 1974 and I was used to more help in prior years from the Justice Department.

Well, what are the remedies? And I do not want to belabor the point because you have had hearings from professionals suggesting remedies for it. But just briefly and to bring up a couple of new ideas; the old idea is that the remedy for institutional abuse is small community homes for people with retardation.

What you may not have heard and what some people even in the profession are not aware of is that group homes for the retarded are nothing new at all, and it is not a fad; it is not an experiment. Beginning in the 1890's, 1910's and 1920's, the institutions themselves put people out into small normal homes in the community. It was the Depression and World War II that made those programs halt. We have forgotten that very important history. So it is not a matter of trying out a new idea; it is a matter of going back to a proven idea.

But there are other things I think the Federal Government and Congress in particular can do. One is to impose treble damages against State officials who violate the civil rights of people in institutions. Antitrust violators pay extra damages, and there is no reason why State officials who violate people's rights should not do the same.

The second is to provide appointed counsel to inmates of mental institutions who bring habeas corpus proceedings in Federal court to secure their release. This would not give mental patients any special treatment, but it would give them the same protection afforded convicted criminals under current U.S. law in such proceedings.

The third recommendation, one that would also cost virtually no money to the Federal Government, is that Congress should specifically criminalize abuse of residents in State institutions and should establish a special prosecutor, independent or semi-independent of the current Department of Justice, to prosecute those cases vigorously.

I have learned, and you mentioned earlier, Senator Weicker, that newspaper exposes and even congressional hearings really do not change things, at least not by themselves. The people of the United States have to realize that people who live in institutions are, No. 1, first-class citizens, and, No. 2, that their vulnerability makes it essential that we protect their rights and that we make sure that we bring them back to the communities from which they came. Thank you.

[The prepared statement of Mr. Ferleger follows:]

April 1, 1985

Testimony of David Ferleger, Esquire
Before the Senate Labor and Human Resources Committee,
Subcommittee on the Handicapped

1. Introduction and Preliminary Comments.

I testify today as a representative of people who, because they are confined in mental institutions, are unable to be here. I come to describe the daily lives of institutionalized people whose voices are stilled because of their unnecessary confinement or death. I come also to suggest remedies for action by the Congress.

* One year ago, in Texas, hospital officials intentionally caused the death of Gladys Piland, a 49 year old resident of a state retardation institution who was married and had an adult son. At Fort Worth State School, Piland became mysteriously ill. She was transferred to a hospital three days later, and five days after that, although the doctors "did not know what was wrong with her," she was taken off a respirator. The records coldly recite: "On 3/20/84 at 11:30 am she was expired." Had it been you or me, we would not have been taken off a respirator and killed after just a few days and with no diagnosis. But Gladys Piland was an inmate of an institution.

* Kenneth Gene Johnson, a 4 year old boy with retardation and blindness, was killed at the Denton Development Center in Texas when he was left unattended in a hallway for a long time,

had a seizure, and choked to death in his wheelchair straps. He died in 1980. The state's investigation showed the institution was grossly negligent but no action has been taken by the state. A manslaughter indictment against the nursing home was dropped. The company running the facility is owned by the conglomerate ARA Services, Inc.

* At New Lisbon Developmental Center in New Jersey, a state facility, J.S., a resident in his thirties, beat to death another resident after taunting and threatening to kill him for months. The murder of A.F. occurred September 10, 1983. The institution knew it was coming and just let it happen.

* Jonathan Savidge, a 12 year old resident of Fort Worth State School, developed a near fatal brain infection after crawling through human waste at the institution. The brain surgery left him half-paralyzed. Although the institution agrees he should be in a foster home, they refuse to provide one and instead keep him unnecessarily in the institution.

* Chris Cockerham is 13 years old. He is a person with retardation and Downs Syndrome. On February 27, 1984, he was brutally beaten and was found with bruises and scratches on his forehead, neck, shoulders, back, buttocks, sides and arms. The skin on the right side of his face and neck was raw and bruised. Both eyes were swollen. Two aides have been indicted for the abuse.

* A white professional upper middle class man was dragged from his Pennsylvania home in Pennsylvania eight months ago, driven four hours to a distant mental hospital, stripped of his clothes except his undershorts, and locked in solitary confinement in a room containing only a mattress on floor. The hospital records themselves confirm that he was repeatedly denied his right to call his lawyer.

* Douglas Ferguson, a young man with retardation, has been locked up in an institution in Pennsylvania unnecessarily. For the past 6 years, the state and county have agreed he should be in a group home but none has been provided.

There are remedies available to Congress which cost the federal government virtually nothing and which would prevent and deter such murderous conditions, abuse and neglect:

a. Impose treble damages against state officials who violate the civil rights of people in institutions. Antitrust violators pay treble damages; why not have people who hurt vulnerable dependent people pay the same?

b. Provide appointed counsel to inmates of mental institutions who bring habeas corpus proceedings in federal court. This would give mental patients the same protection afforded convicted criminals in such proceedings.

c. Congress should specifically criminalize abuse of residents of state institutions and should establish a Special Prosecutor, semi-independent of the Justice Department, to prosecute such cases vigorously.

2. Biographical Background on David Ferleger, Esquire

I testify today as a representative of people who, because they are confined in mental institutions, are unable to be here. I come to describe the daily lives of institutionalized people whose voices are stilled because of their unnecessary confinement and death. Additionally, I will convey to the Committee information regarding the history of mental institutions and the rights of those confined within their walls. Finally, I will suggest to the Committee a number of ways it can promote legal rights and dignity for institutionalized people.

As an attorney whose legal practice is devoted to the rights of developmentally disabled people, I am well acquainted with the tragic consequences of institutionalized care in America.[1] I have argued before the United States Supreme Court on five occasions.[2] I have represented disabled people in Pennsylvania, Massachusetts, California, Kentucky, Texas and other states in litigation designed to secure appropriate treatment, respect and dignity. Most recently, Steven Schwartz, Barbara Hoffman and I filed an amicus brief in the United States Supreme Court in *City of Cleburne v. Cleburne Living Center* on behalf of four disabilities organizations and institutionalized plaintiffs in thirteen cases in nine states.

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[1] *See* attachments 1, 2 and 3: Curriculum vitae Of David Ferleger; Ferleger, *Anti-Institutionalization and the Supreme Court*, 14 RUTGERS L. J. 595 (1983); Ferleger and Boyd, *Anti-Institutionalization: The Promise of the Pennhurst Case*, 31 STAN. L. REV. 717 (1979).

[2] *Halderman v. Pennhurst State School and Hospital*, 451 U.S. 1 (1981); 465 U.S. ___ (1984) (three arguments); *Bartley v. Kremens*, 431 U.S. 119 (1977); and *Institutionalized Juveniles v. Secretary of Public Welfare*, 442 U.S. 640 (1979).

In addition to private practice, I teach mental health law at New York University School of Law and am currently president of two organizations which serve people with disabilities. The National Association of Rights Protection and Advocacy is the only advocacy organization which assists both people with mental illness and people with retardation in exercising their legal rights. NARPA's membership includes top mental health and mental retardation public officials, mental health professionals and consumers. NARPA sponsors this country's only regular conference on the rights of people with disabilities. The Foundation for Dignity is a charitable organization devoted to public and professional education regarding the needs and rights of people with disabilities.

3. *Examples of Institutional Life*

Institutionalization has a dramatic, and even deadly, impact on the lives of people with disabilities who are denied the right to live in a less restrictive environment. The problems of institutions are evident in both public and private facilities for the mentally retarded and the mentally ill.

Individual stories exemplify the tragedy of daily institutional life. You and the people here today will learn a little bit about the lives of the specific people behind these true and terrifying tales. The tragedy is that these stories are all too representative of the horrors of life in America's mental institutions. For each person I mention today, there are wards full of thousands of silent figures suffering unnecessarily behind institutional walls. I have seen them and, if you visit, you see them too.

a. Kenneth Gene Johnson

Kenneth Gene Johnson, a young boy with retardation, blindness and scoliosis, was four years old when he died at Denton Development Center (DDC) in Denton, Texas in October, 1980. A state investigation into Kenneth's death revealed that the negligence of DDC staff caused Kenneth to strangle to death on his wheelchair straps. Criminal indictments for manslaughter were not pursued despite evidence detailing DDC's negligence, including improper maintenance of Kenneth's wheelchair, failure to give Kenneth prescribed anti-convulsant medication, leaving Kenneth alone in a hallway, failing to train properly direct care aides and hiring people with criminal convictions for public lewdness and weapons offenses as direct care aides. DDC continues today to operate as a large, private "nursing home" institution for people with disabilities. DDC is run by a company which is owned by the conglomerate ARA Services, Inc.

I visited DDC two months ago and found it a dismal awful place with small children laying on the floor inactive, ignored by staff, or crowded into small "activity" rooms with no direction. In one bedroom I saw there is a wooden cage in which a resident sleeps.

Kenneth had a seizure disorder which required, for control of seizures, regular monitored receipt of anti-seizure medication. He had a particular problem with coughing and choking, especially during eating. Because of his special needs, Kenneth's parents, Roy and Vicki Johnson, placed him in Denton Development Center. They advised DDC of Kenneth's need for constant and personal supervision, the proper use of certain wheelchair straps, the need for anti-seizure medication and his vulnerability to injury and danger. Despite the parent's concern and admonitions, DDC removed the proper straps from Kenny's wheelchair and replaced them with dangerous, improperly threaded straps.

According to the state's investigation, on October 30, 1980, Kenneth was wheeled from the dining area into a hallway, where he was left unattended for twenty-five minutes. Dr. Rafael Toledo, DDC's former medical consultant, later told state investigators that a patient like Kenneth should never be unattended while awake. Because DDC had neglected to maintain Kenneth's anti-convulsant blood level within the therapeutic range, Kenneth suffered a seizure.

Kenneth slipped down in his wheelchair because he had not been strapped in properly. His neck became entangled in the straps and he slowly strangled to death. He was discovered by DDC staff with the Y-strap, used to maintain body position, around his throat, his feet secured by ankle straps and his body weight supported by the strap on his neck. He had red marks on his neck and his skin was white in color. He was pronounced dead later that day.

Kenneth died a slow, torturous death two months short of his fifth birthday because of DDC's negligence. State investigators concluded that DDC was negligent in six areas: 1) Despite his parent's admonitions and Kenneth's special needs, he was left unattended in a hallway for approximately 25 minutes. 2) DDC failed to properly medicate Kenneth as determined by anti-convulsant blood level tests. 3) Professional staff failed to take corrective action when blood tests showed that Kenneth was not receiving medication required to control his seizures. 4) Professional staff to alert direct care aides to Kenneth's specific problems. 5) Professional staff failed to document indicents requiring attention. 6) Professional staff failed to adequately train direct care staff. Despite these conclusions that DDC's negligence caused Kenneth's death, DDC still operates today without interruption or sanctions. Meanwhile, Roy and Vicki Johnson must endure the loss of their son.

b. Jonathan Savidge

Bill and Felicia Savidge of Hurst, Texas nearly lost their twelve year-old son, Jonathan, due to the neglect of another institution, Fort Worth State School, a state facility for approximately five hundred people with retardation in Fort Worth, Texas. Jonathan developed a near fatal brain infection as a result of the unsanitary, bacteria-infested conditions at Fort Worth State School. The Superintendent himself has testified to seeing puddles of urine on the wards. Although Jonathan survived brain surgery, the infection left him with serious handicaps, including paralysis of his right side.

Jonathan entered the institution on September 2, 1980 because the State of Texas failed to provide him with a more appropriate, less restrictive alternative to the brutal institutional regime of Fort Worth State School. He still is confined there today, despite the fact that the institution says he can live, and should live, in a family-style home in the community.

Upon entering the institution, Jonathan was able to walk with the assistance of braces and was described by staff as "a particularly ambulatory client." As a result of living under filthy, bacteria-infested and grossly unhygenic conditions at the institution, Jonathan developed an infection which produced festering boils on various parts of his body. Fort Worth State School staff negligently failed to respond adequately to Jonathan's immediate medical needs, causing this infection to spread throughout his entire blood stream. Cysts developed in Jonathan's heart and brain as a result of the infection, necessitating brain surgery. Jonathan continues to require painful and costly medical treatment, most recently including cardiac catheterization this past January.

As a result of gross lack of medical care and the unsanitary conditions at Fort Worth State School, Jonathan became paralyzed on his right side. Today, he is totally non-ambulatory. He is unable to control the movement of his wheelchair with his one operative hand, and he cannot support his weight on his paralyzed side. This latter condition has, in turn, led to Jonathan's developing scoliosis, a spinal condition which, if uncorrected in a child of Jonathan's age, leads to irreversible curvature of the spine and severe limitations on mobility, use of the body and participation in social and community activities.

In addition to the devastating physical effects of confinement, Jonathan suffered from a loss of habilitative skills while confined at Fort Worth State School. Jonathan possessed a number of self-help skills and limited language ability when he entered the institution. However, these skills declined during his confinement because the state school provided inadequate programming. The maximum time spent in programmed activities three days a week was two hours and twenty-five minutes despite the fact that professional standards require that Jonathan receive a minimum of forty hours per week in seven days of active programming. Even less time was spent during the rest of the week and when staff was unavailable. A proper habilitation program would include dressing skills (skills which Jonathan possessed when he entered the institution), bathing and other basic skills.

However, Fort Worth State School offered only feeding and toileting programming to Jonathan.

Although Jonathan was ambulatory when he entered the institution, once he became partially paralysed, he spent 90% of his time confined to a 15' by 15' carpeted area, strapped in a wheelchair which was not appropriately fitted or maintained. The inadequacy of staff and programming resulted in Jonathan's harm, deterioration and regression. Instead of providing Jonathan a safe environment designed to develop his maximum potential, Jonathan suffered nearly fatal physical harm and crippling regression in habilitative skills.

Two experts concluded that the treatment Jonathan received at Fort Worth was a departure from applicable professional standards. Linda Glenn, former Assistant Commissioner of Mental Health for the Commonwealth of Massachusetts who supervised all institutional and community services for mental retardation and mental health in Massachusetts, found that Fort Worth failed to deliver the services which even it recognized Jonathan required. She described the paucity of services as "totally inadequate."[3]

Sue Gant, a nationally recognized mental retardation expert and Special Master to the Federal District Court in Gary W. v. Louisiana, agreed with Dr. Glenn that Jonathan was irreparably harmed by his confinement at Fort Worth, instead of given professional services designed to enable him to develop to his maximum potential.[4] Both experts agreed with the state's assessment that Jonathan should be moved immediately to the community to prevent further harm and regression. The findings of the two experts were uncontradicted in court.

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[3] Attachment 4.

c. Chris Cockerham

Chris Cockerham is a thirteen year old boy with Downs Syndrome and retardation who was brutally beaten one year ago during his confinement to Fort Worth State School. On the morning of February 27, 1984, staff routinely woke Chris at 5:45 for his morning bath. As the attached photographs disclose, Chris was discovered covered with bruises and scratches on his forehead, face, neck, shoulders, back, buttocks, sides and arms.[5] The skin on the right side of his face and neck was raw and bruised. Both of his eyes were swollen. The nature and location of his extensive injuries reflected that his injuries could not have been self-inflicted or inflicted by another resident of Fort Worth State School. Chris, who stands only 4'3" was extensively beaten from head to toe.

We appealed to the U.S. Justice Department's Civil Rights Division for help and were rebuffed. We wrote in March, 1984, provided the pictures and information about other abuse at Fort

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[4] Attachment 5.

[5] Attachment 6.

Worth.[6] Several months later were told by Justice that the United States would not act.

On May 8, 1984, a Tarrant County Grand Jury returned indictments against Sheila Yvonne Jenkins and Angela Kay Culton, the only two staff members on duty on Chris' ward the evening he was beaten. They were charged in connection with the unprovoked assault against the young boy. They were suspended with pay and continued to be paid awaiting their trial. On August 8, 1984, Chris' parents moved him to the first available alternative residence, a small group home for several boys with retardation in Arlington, Texas. Chris now attends special public school classes and lives in a safe, home-like environment.

As a result of the beating, Chris endured great pain and suffered a hearing loss. He was unable to sleep for over forty-eight hours following the assault and still has trouble sleeping today. Chris' verbal, social and self-help skills declined markedly. When he entered the institution in 1982, Chris had many behavioral, social and verbal skills. Chris possessed several self-help skills, such as toileting, washing his hands, brushing his teeth and some dressing skills.

After two years at the institution, Chris had lost many of these skills. In addition to the beating, Chris' regression is due to the debilitating environment at the institution: insufficient staff and programming, lack of individual training, inadequate dietary care, non-existent educational services and unsanitary conditions.

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[6] Attachment 7.

d. Murder in New Jersey

Brutality and untimely deaths are not uncommon at large public institutions for people with retardation. At New Lisbon Developmental Center in New Lisbon, New Jersey, an institution for more than 700 disabled people, one resident beat to death another resident, after taunting and threatening to kill him for months.

J.S., a man in his thirties, was a constant behavioral problem on one ward at New Lisbon. State investigators found that from May 29, 1983 to September 10, 1983, at least nine incident reports were filed by staff detailing J.S.'s assaults on staff and residents. Although J.S. attacked several residents, he focussed much of his abuse on A.F., another man on his ward. On May 29, 1983, J.S. beat and kicked A.F. because A.F. was granted a pass. After staff finally pulled J.S. away, he vowed to "get A.F." later that night. On July 12, 1983, J.S. punched A.F. in the face, kicked him in the back and repeated his threatening remarks. One September night, J.S. attacked A.F. in the shower because he was envious that A.F. did not have to shave. When A.F. fell to the shower floor, J.S. continued to kick him. The following day, September 10, 1983, J.S. beat A.F. to death.

Despite J.S.'s long record of violence over the course of the summer, and his particular animosity towards A.F., little was done to protect his victims from attack. J.S. was allowed to remain on the ward to taunt and torture other residents. The result was a horrible and most easily avoided murder.

Institutions for the mentally ill are as wrought with abuse as those for people with retardation. Even the most basic rights are denied people who are involuntarily committed. In Pennsylvania, two armed sheriffs dragged one man from his home, drove him four hours away to Western Psychiatric Institute and Clinic in Pittsburgh, stripped him of all his clothes except his undershorts and locked him in seclusion for thirty-six hours in a room containing only a mattress on the floor.

Twice that evening, the man asked to call his attorney and was twice denied, a clear violation of Pennsylvania law which guarantees a person who is involuntarily committed the "right to communicate immediately with others" and "reasonable use of the telephone."[7] His hospital records reflected on the night he was admitted that he was "demanding the use of a phone, wants to notify his wife that he is here ... explained that we would relay message."

f. Douglas Ferguson

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[7] 50 P.S. 7302(c)

The need for federal intervention to protect institutionalized people is great. States and counties have not committed the personnel and monetary resources required to meet the needs of America's developmentally disabled. For example, Douglas Ferguson has been waiting nearly six years to leave an institution for a home in the community.

Douglas, a young institutionalized man with retardation from suburban Philadelphia, was referred for community placement in the spring of 1979 because his needs could best be served in the community. His County Core Team and individual Program Plan team still conclude today that he should reside in a community residence. Despite these recommendations, nearly six years have passed without significant progress. The young man is still confined to the same inadequate institution where he is denied the right to live in a normal environment.

The county took few steps to place him until his parents hired me to persuade local officials to pursue available and appropriate solutions. Not until I brought to the attention of the county a Commonwealth Court case which held that the state must fund a county program request for community services for a person with retardation did the county even request state funding for community placement for Douglas.[8] To date, we have no indication from the state that it will promptly provide funding for community placement for this young man and thousands of others who remain unrepresented.

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[8] In re Sauers, 447 A.2d 1132 (Pa. Cmwlth 1982).

4. The Movement Away from Large Institutions

People with disabilities have long been subjected to prejudice, exclusion and unequal treatment. Although most people with retardation and mental illness live among us as neighbors who share the benefits and burdens of the community, a small minority are confined to large institutions where they receive unnecessary and ineffective care.

Prior to the twentieth century, families had few options for taking care of their mentally disabled relatives. For many years in some parts of the country, large public institutions provided the only alternative for an average income family faced with the need to care for a disabled relative outside the home.[9]

Conditions at some institutions have improved in the wake of mounting family, judicial and legislative pressures. However, serious problems still persist. Despite weak attempts to gain legitimacy as a provider of custodial care, that image of institutions has been tarnished by public investigation, scholarly studies and judicial findings.[10] The dehumanization and damaging consequences of institutionalization are now widely known and accepted.[11]

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[9] Craig & McCarver, *Community Placement and Adjustment of Deinstitutionalized Clients: Issues and Findings* in 12 INTERNATIONAL REVIEW OF RESEARCH IN MENTAL RETARDATION 95 (N. Ellis and N. Bray eds. 1984).

[10] Taylor and Bogdan, *Defending Illusions: The Institution's*

The death rate in institutions is unusually high.[12] Neglect and epidemic disease contibute to diminished life expectancy, failure to correct orthopedic abnormalities renders residents less functional and poor dental care causes loss of teeth.[13] The misuse of psychotrophic drugs causes permanent harm and disrupts habilitation.[14] Institutional residents with severe and profound retardation fail to develop fundamental life skills, and actually lose skills they possessed when they entered the institution.[15] The starkness, brutalility and abnormalility of institutional life breed regression and abuse instead of habilitation and dignity.

Struggle for Survival, 39 HUM. ORGANIZATION 209, 211 (1980).

[11] See Ferleger, *Anti-Institutionalization and the Supreme Court*, 14 RUT. L.J. 595, 603 (1983).

[12] *See, e.g.* Balakrishnan and Wolf, *Life Expectancy of Mentally Retarded Persons in Canadian Institutions*, 80 AM. J. MENTAL DEFICIENCY 650 (1976) (mortality rate double that of general population); Foreman and Akesson, *Mortality Rate of the Mentally Deficient: A Study of 12,903 Institutionalized Subjects*, 14 J. MNETAL DEFICIENCY RESEARCH 276 (1970), Tarjan, *Natural History of Mental Retardation in a State Hospital Revisited: Releases and Deaths in Two Admission Groups, Ten Years Apart*, 117 AM. J. DISEASES CHILDREN 609 (1969).

[13] Nelson and Crocker, *The Mental Care of Mentally Retarded Persons in Public Residential Facilities* 299 NEW ENG. J. MED. 1039 (1978).

[14] R. Scheerenberger, *Public Residential Services for the Mentally Retarded, 1982*, 3-4 (1983).

[15] Ferleger, *supra*. at 606.

Conditions at public institutions for the retarded are no better, and often worse, than private institutions. Protracted litigation has documented the horrors of daily life at facilities such as Willowbrook State School (now known as Staten Island Development Center) in New York and Pennhurst State School and Hospital (now know as Pennhurst Center) in Pennsylvania[16] One resident of Pennhurst, a young retarded man named Nicholas Romeo, suffered at least sixty-three serious injuries during a twenty-eight month period, including several broken bones, bites and scratches.[17]

A growing number of states have begun to shift resources from institutional to community care for developmentally disabled people. As a result of the skyrocketing costs of institutional care and the economic incentives for community living, reducing the size of residential settings for people with retardation has gained general acceptance among most state and local officials.[18] Professor Gunnar Dybwad, a worker and observer of institutions for the last fifty years, concludes, "Whether it is called a state school, a regional center, a training school, or a developmental center, the mental retardation institution typically developed in our country in practically every state over the past 100 years, is dead."[19] "In many states deinstitutionalization is very nearly an accomplished fact. Several, including Maryland, Minnesota, Florida, Michigan, Illinois, and Pennsylvania have closed, or intend to close, public residential facilities to be replaced by community alternatives."[20]

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[16] *See New York Ass'n for Retarded Children v. Carey*, 393 F. Supp. 715 (E.D. N.Y. 1979), *aff'd* 596 F.2d 27 (2d Cir.), *cert.denied*, 444 U.S. 836 (1979); *Halderman v. Pennhurst*, *supra.*

[17] *Youngberg v. Romeo*, 457 U.S. 307 (1982).

[18] Latib, Conroy and Weiss, *Family Attitudes toward Deinstitutionalization*, in 12 INTERNATIONAL REVIEW OF RESEARCH IN MENTAL RETARDATION 67 (N. Ellis and N. Bray eds. 1984).

The number of people living in retardation institutions, as well as the population of each institution, has declined over the past twenty years. States have just begun to heed the call of professionals, families and courts that institutions are an unnecessary, costly and inappropriate means of responding to the needs of disabled people. Federal constitutional law supports state attempts to protect people with retardation from harm by not needlessly institutionalizing them.[21] A growing number of courts have found that large institutions for people with retardation must be supplemented and/or replaced with community care because institutions result in unconstitutional confinement, regression of skills, physical abuse, and on some occasions, unnatural death.

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19. Address by Gunnar Dybwad, *A Society Without Institutions?*, Residential Alternatives symposium, University of Hartford, at 2 (Dec. 9, 1978).

20. Craig and McCarver, *Community Placement and Adjustment of Deinstitutionalized Clients: Issues and Findings* in 12 INTERNATIONAL REVIEW OF RESEARCH IN MENTAL RETARDATION 95, 99 (N. Ellis and N. Bray eds. 1984).

21. *Youngberg v. Romeo, supra.*; *Parham v. J.R.*, 422 U.S. 584, 600 (1979) ("substantial liberty interest in not being confined unnecessarily for medical treatment").

5. What Congress Can Do to Protect the Rights of People with Disabilities

Congress should join and encourage the movement to replace costly, ineffective and dangerous institutions with appropriate community care for people with disabilities. The most critical remedy for such murderous conditions, abuse and neglect is quite simply the replacement of institutions with a network of supervised quality community services. Such services are more effective and less costly than institutions.

But there are other remedies which would cost the federal government virtually nothing and which would be effective to prevent, deter and, if necessary, punish those who violate the rights of people in institutions.

First, institutionalized people whose civil rights have been violated should be entitled to double or treble damages under 42 U.S.C. 1983. Congress has recognized the need for multiple damages in areas such as anti-trust litigation in which social policy goals are to discourage unfair practices which take place behind corporate walls. Multiple damages are similarly necessary to deter denial of constitutional rights behind institutional walls. The United States Supreme Court has recognized that an involuntarily committed person with retardation has a liberty interest in safety and freedom from bodily restraint.[22] Remedies for violation of these liberty interests should send a stern message to the perpetrator as well as compensate the victim.

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[22] *Youngberg v. Romeo, supra.*

Second, all mental patients incarcerated by the state who bring habeas corpus proceedings in federal court should have the right to adequate representation of counsel. The Federal Criminal Justice Act extends the right to counsel to state prisoners who file a federal writ of habeas corpus.[23] Mental patients should be given the same right to counsel protections accorded convicted criminals in federal courts.

Third, Congress should specifically criminalize abuse of residents of state institutions. Such a specific federal statute would promote the right of institutionalized people to be free from harm as recognized by the United States Supreme Court in Romeo. The general federal criminal civil rights statute, a century old, has been used only once by the Justice Department and is not taken seriously by United States Attorneys.

Fourth, Congress should establish a Special Prosecutor's Office, semi-independent from the Justice Department, to prosecute cases of abuse in institutions.

Fifth, Congress should exercise its authority under the Fourteenth Amendment to extend federal court jurisdiction to pendent state claims in civil rights suits against state officials. Federal court exercise of such pendent jurisdiction was common until struck down recently by the United States Supreme Court in Pennhurst.[24] Congressional restoration of pendent jurisdiction would in effect overturn this holding in Pennhurst and promote judicial economy by permitting plaintiffs to litigate all related claims in one federal court proceeding.

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[23] Criminal Justice Act, 18 U.S.C. 3006A; Abduc v. Lane, 468 F. Supp. 33 (E.D. Tenn. 1978), aff'd 588 F.2d 1178 (6th Cir. 1978).

A history of abuse and deprivation has shown that the rights of people with disabilities will not be ensured if left solely to local officials. The need for federal intervention is critical and immediate.

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[24] Halderman v.Pennhurst State School and Hospital, 465 U.S. ___ (1984).

Senator **Weicker**. Thank you. Senator Thurmond.

Senator **Thurmond**. Thank you very much, Mr. Chairman. I have a brief statement. Today the subcommittee begins what is scheduled to be 3 days of hearings on the care and advocacy for mentally disabled persons in institutions. The subcommittee will be receiving testimony from witnesses who have special knowledge of instances of abuse of the mentally disabled.

Among the witnesses who will be testifying today will be a prominent member of the South Carolina State Senate. I would like to welcome Senator Arthur Ravenel, Jr. to our Nation's Capital and say that I look forward to his testimony.

Senator Ravenel has given considerable attention to the matter of the care and treatment of the mentally handicapped, and his testimony will help shed light on this important matter.

In past hearings this subcommittee has heard from individuals from the Department of Health and Human Services and the Department of Justice. Mr. Chairman, I think it might be appropriate, reasonable, and fair in light of the testimony this subcommittee will be receiving these next few days that the Federal agencies and the State agencies involved have an opportunity to respond to this testimony if they desire to do so.

With respect to the problems identified by a recent Justice Department investigation of the South Carolina State hospital, about which I believe Senator Ravenel will have more to say in his testimony, I ask unanimous consent that a copy of a letter I have received from South Carolina Governor Richard W. Riley be placed in the hearing record following my remarks.

The letter outlines the actions taken by the State of South Carolina to address the deficiencies in the State hospital, which I understand are typical of the problems which may exist in a number of other States.

Unfortunately, Mr. Chairman, because of conflicts in my schedule I will not be able to stay for the entire hearing. I do, however, look forward to reviewing the hearing testimony and carefully following any development relating to this matter.

I want to thank all of the witnesses for their appearance today, and I want to say that recently we have passed through the Senate, as you know, a bill on missing children and care of children, and I am vitally interested in children. We have four children ourselves from 9 to 14 years of age, and steps must be taken to see that they are properly cared for and that their lives are properly protected from officials at any level of government. Thank you very much.

[The letter refered to follows:]

State of South Carolina

Office of the Governor

Richard W. Riley
Governor

Post Office Box 11450
Columbia 29211

March 28, 1985

The Honorable Strom Thurmond
United States Senate
Senate Office Building
Washington, D.C. 20515

Dear Strom:

On November 23, 1984, the United States Department of Justice provided me with a report of their investigation of conditions at the South Carolina State Hospital as of January, 1984. A copy of this letter is enclosed. Since November, representatives of my office, the Department of Mental Health and the State Attorney General have met on several occasions with officials of the Justice Department.

Assistant Attorney General William Bradford Reynolds communicated in his letter of November 23 that, throughout the entire process, officials of the State of South Carolina, including the Department of Mental Health, have exhibited the professionalism and cooperation which form the foundation of the joint Federal and State effort envisioned by the Civil Rights of Institutionalized Persons Act (CRIPA). We are now at the point of responding to the specific remedial measures outlined in his letter. The plan will be delivered to the Justice Department on Monday, April 1, 1985. We feel that if the State implements our full plan as herein provided, the concerns of the Justice Department would be met.

Under separate cover I am providing you our Remedial Action Plan, with supporting documents, which details the activities discussed and modified, as appropriate, in the aforementioned meetings. You will note that the goals set by the Department of Mental Health exceed the standards envisioned by CRIPA. We are confident that necessary levels of improvement will be met or exceeded by the end of this calendar year.

The plans which are detailed below, and more comprehensively in the full Remedial Action Plan, address five subject areas identified in consultation with the Department of Justice officials and experts: (1) reduction of patient population, (2) enhancement of professional staff, (3) implementation of psychotropic medication safeguards, (4) enhanced patient protection and (5) implementation of seclusion/restraint safeguards. Accordingly, since the Department of Justice visited South Carolina State Hospital in late 1983/early 1984, the following changes have been initiated:

- A program has been implemented to reduce the hospital patient population from 1,100 to 700 patients by the end of this calendar year. The Ways and Means Committee of the South Carolina General Assembly has approved a $425,000 appropriation for young adult treatment homes. The new 204 bed Harris Psychiatric Hospital will open in June 1985, and will absorb a minimum of 80 patients now at the South Carolina State Hospital.
- Plans are being implemented to improve the quantity/quality of professional staff dramatically. The Ways and Means Committee has approved a $3.4 million appropriation to enhance staffing and a net increase of 22 Registered Nurses has already been achieved.
- Extensive staff training in psychopharmacology has been implemented and the Ways and Means Committee has approved a $500,000 appropriation to fund a computerized pharmacy system.
- A new and highly competent superintendent has structured a new patient classification and treatment system which has dramatically decreased patient incidents and enhanced staff accountability. Additionally, the South Carolina Legislature has provided State Law Enforcement Division oversight for Public Safety functions at the South Carolina State Hospital.
- The new hospital superintendent has implemented exceedingly restrictive policies governing the use of restraint and seclusion which far exceed guidelines promulgated by the national accrediting bodies.

The following paragraphs outline the program specifics which have been accomplished or initiated to address each and every deficiency observed by the Justice Department staff and medical experts. Those objectives which have not been accomplished will be completed before the end of this calendar year.

Patient Reductions: During the last two years, the Department of Mental Health has initiated concrete plans which would reduce the size of the South Carolina State Hospital to 700 patients. Such a reduction is deemed necessary to provide the highest quality psychiatric hospital care in that the State's experience has been that larger institutions present unique and difficult management and service problems. Among the plans that are reaching fruition are:

1. Harris Psychiatric Hospital will open in July, 1985 to provide the acute care needs of children, adults and elderly in 14 of the State's 46 counties. The other acute admissions from the State (32 counties) will continue to be served by Bryan Psychiatric Hospital, thus removing from the South Carolina State Hospital a significant admissions load. With 206 beds, Harris Psychiatric Hospital will reduce the average daily census at South Carolina State Hospital by 80 patients (Section XI-A).

2. The House Ways and Means Committee has approved the appropriation of $425,000 (Attachment XI-1) to begin high-structured residential facilities to serve young, chronic mentally ill adults who otherwise would require institutional care (Section XI-A). The four programs, which will be operational within this calendar year, are designed to serve 140 residents, 125 of whom have been identified and will be discharged from the South Carolina State Hospital.

3. The State Medicaid agency (Health and Human Services Finance Commission) has structured with the Department of Mental Health a Medicaid service termed "Personal Care" which, upon the approval of the Regional Office of the Health Care Financing Administration, will be available to community care home operators to enhance programs sufficiently that patients, who otherwise would have spent a longer period in the hospital, can be moved to those homes. Funded up to $100.00 per week per resident ($4.00 per hour up to four hours per day up to five days per week), community care home programs will be enhanced to provide living skills training and activity training which heretofore have been provided only in the psychiatric hospital. Space is currently available in community care homes across the State and the hospital has identified patients for the 80 slots which will be available July 1, 1985 (Section XI-A) through this program and another 20 patients through Community Support Program funding (Section XI-A). In that all 100 assignments will be from the South Carolina State Hospital, the census will be reduced by that number.

4. The Department of Mental Health has recommended two changes to the mental health statutes which would impact favorably upon the patient census. One would provide for local screening of patients being considered for emergency admission to encourage the utilization of community resources which meet the patients' needs and divert patients who are in medical distress. The other would allow appropriate involuntary patients to convert to voluntary status. In addition to therapeutic advantages, this statutory change would allow patients to be treated in the least restrictive environment consistent with the patients' needs. The combined effect of these proposals is anticipated to be a net reduction in the patient population of 50.

All of these actions combine to reduce the demand on the South Carolina State Hospital by 355 patients at any one time. Based on the patient census on March 19, 1985, had these actions already transpired, the census at the hospital would be 667. Based on current progress, we are planning for a census of 700 or below by the end of 1985.

Staffing and Staff Qualifications: Significant improvements have been made in staff-to-patient ratios, including physicians, psychologists, M.S.W. social workers and both registered nurses and licensed practical nurses. A major State effort is under way to increase salaries, as appropriate, to more competitive levels and to recruit the additional professionals needed.

The hospital has requested an increase from the Legislature of $3,397,283 and 166 positions. This request has been approved by the House Ways and Means Committee and there is every assurance from the House and Senate leadership that the budget/personnel increases will be included in the State budget to be effective July 1, 1985 (Section VI).

Already dramatic staffing increases have occurred. Since July, 1984, the number of registered nurses has been increased by 22. This has resulted in attainment of a hospital-wide direct care R.N.-to-patient ratio of less than 1:40 on the day and evening shifts. On those shifts, the hospital goals are being approached or exceeded on the Child and Adolescent Unit (1:10), the Admissions Unit (1:32) and the acute portion of the Forensic Unit (1:15). In all the continuing care services of the hospital, the goal of 1:40 R.N.-to-patient ratio is being approached (currently 1:40). There is currently one R.N. assigned to every unit for the night shift (Section IV-A).

Active recruiting of registered nurses remains a priority of the hospital and State government. In order to ensure that the ratios will be met 24 hours per day, 365 days per year, the hospital needs to employ an additional 14 registered nurses. A Southeastern regional promotional and recruiting campaign will begin in April and is expected to achieve the required result (Section IV-A).

The hospital currently has a physician-to-patient ratio of approximately 1:38 with 27 full-time physicians and numerous part-time, contractual physicians including child psychiatrists, forensic psychiatrists and a pediatrician. With the continuing reduction in patient census, by the end of 1985, a 1:25 physician-to-patient ratio will be attained (Section I-A).

The State Division of Human Resource Management is currently reclassifying all job categories for psychiatrists and Ph.D. level Clinical Psychologists whereby, effective July 1, 1985, the several classes in the respective disciplines will be absolutely competitive with Georgia, North Carolina and Virginia, which are South Carolina's major head-to-head competitors. In addition, special classifications of Master Clinician for psychiatry and clinical psychology are being established at salaries up to 35% above regular pay grades in order that the hospital can recruit well-credentialed specialists in areas such as forensics and child and adolescent services. These special category persons are intended to be "magnets" in attracting well qualified young professionals in the respective disciplines.

Concurrently the quality of the medical staff has been, and continues to be, improved. In addition to extensive training by nationally-recognized consultants and faculty from the State's psychiatric residency program (Section I-C), recruiting is focusing intensely upon highly qualified physicians. An employment offer has been made to an experienced, well qualified, board-certified psychiatrist for the position of Director of Professional Services and his answer is expected in early April (Section I-A).

Within psychological services, the hospital has achieved its goal in staffing the acute care units of Admissions, Child and Adolescent and Forensic at 1:35. In April the hospital will meet its goal of having four licensed Ph.D. psychologists on the staff. There is every reason to believe that by the end of 1985 the hospital will meet its staffing goals in psychology with highly qualified professionals (Section II-A).

The number of M.S.W. social workers has increased by four since July, 1984 to a total of 17. With the intense recruiting effort, the hospital anticipates meeting its goal of 20 prior to the end of the year (Section III-A). Further, with the managerial emphasis on enhanced clinical services, the M.S.W. social workers have been assigned more therapeutic duties with patients and families and B.A. staff are performing the discharge coordination duties (Section III-C).

Use of Psychotropic Drugs: Extensive training of physicians and other professional staff in psychopharmacology has already taken place with additional training planned systematically. In conjunction with the increase in direct-care physicians/psychiatrists (Section I) to an overall physician-to-patient ratio of 1:38, the increase in registered nurses in direct care to 78 (Section IV; overall ratio of 1:39 on the day and evening shifts) and the assignment of patients with similar needs to the same unit and staff with particular expertise to the most appropriate unit (Section X), psychopharmacological treatment has improved greatly.

Extensive training of physicians and other professional staff has already occurred. Dr. Arnold Goldstein from Syracuse University has conducted training on structured learning therapy (April 12 & 13, 1984); Dr. Robert Mullaly has conducted training on patient education (May 5 & 6 1984); Dr. Brands from the National Institute of Mental Health has conducted training on clinical documentation (November 29, 1984); Dr Robert Scott from the University of Pennsylvania has consulted with all treatment teams in effective treatment planning (January 23 & 24, 1985) and team functioning (March 14 & 15, 1985 and will return in late April 1985 for additional training sessions); Dr. Robert Granacher of the Kentucky School of Medicine has conducted training on psychopharmacology and tardive dyskinesia (December 27 & 28, 1984; February 28 and March 1, 1985) and is scheduled to provide more training; and staff from the Department of Mental Health's Division of Alcohol and Drug Addiction will be conducting training on treatment of alcohol and substance abuse patients (Sections I-C, II-C, IV-C).

The pharmacy staff of the hospital which is being increased from three to seven, have become much more active in review, consultation and education. Registered pharmacists of the hospital are conducting daily "Understanding Your Medication" classes in the Patient and Family Education Center (Section VII-B), meeting individually with patients where indicated by the patient or staff (Section VII-B), providing a weekly newsletter on developments in pharmacology (Section VII-B; Appendix VII-1) and reviewing individual patient records in order to formally consult with the prescribing physician concerning any questions of dosages, interactions or use of two or more medications simultaneously (Section VII-D).

The hospital is revising its procedures to ensure adequate documentation and justification for all pharmacological practice. By July 1, 1985 procedures will be implemented which ensure adherence to the Informed Consent policy requiring that all patients are individually and fully informed of potential benefits and possible side effects anytime medications are begun or changed (Section VII-B). The current policy which is under revision and will be effective prior to July 1, 1985, assures justification of any physician orders for PRN (as needed) medication and justification by nursing staff of the necessary conditions which led to any administration of medications under a PRN order (Section VII-C).

The House Ways and Means Committee has approved an appropriation of $500,000 for implementation of an automated data processing system for the hospital pharmacy. The State Office of Information Resources Management is working with the Department of Mental Health to obtain the best possible computer equipment and software which will provide prospective evaluation of any prescriptions for drug interactions, drug allergies, duplication of medications and excessive dosages (Section VII-D). In conjunction with the planned change to a unit dose system during 1985 (Section VII-D,2), the oversight of pharmacological practice will become fully proactive rather than retroactive. Physician supervision and training will be further enhanced with the computer system which will provide pharmacists and medical supervisors with reports of patient medication profiles, physician prescribing records and a pharmacy inventory control system.

In October, 1983 the Quality Assurance component of the hospital began documentation audits to ascertain whether patient files contained adequate justification of the diagnosis, planned course of treatment and medication prescribed. To date, the audit of the Forensic Unit has been completed and the audit of the Admissions Unit is underway; eventually all seven units will be audited. The result of these audits is being utilized by the hospital to identify those patients in need of clinical review and documentation to ensure that diagnoses are proper and that any psychotropic medications prescribed are appropriate to the diagnosis and planned course of treatment (Section VII-A).

Protection from Harm: With the arrival of a highly competent and experienced new Superintendent on January 3, 1984, a total reorganization of the hospital began. A new Director of Nursing was employed July, 1984 and proved instrumental in recruitment; licensed nursing personnel increased to 74 registered nurses in direct care and 86 licensed practical nurses employed in direct care (Section IV-3).

During 1984 all hospital patients were assessed and classified based on individual treatment needs. On November 2, 1984, the hospital was reorganized into seven distinct treatment units with patients assigned to the unit which will meet their needs and staff assigned based on area of clinical expertise. On each unit, a Unit Director is responsible to the Superintendent for treatment planning, program implementation and staff supervision, including compliance with all hospital policies and procedures (Section IX).

Concurrent with the establishment of specialized treatment units, professional staff, including medicine, psychology, social work and activity therapy, which had previously been located in central locations, were individually assigned and moved to the individual treatment unit most appropriate to their expertise. As a result, staff accountability and performance expectations have been significantly improved as indicated by the increased interaction of staff with patients in the treatment programs. Unit Directors and professional discipline directors have redefined the duties and expectations of the individual professional staff members to ensure performance of duties, clinical supervision and training and ensured accountability (Sections I-B, II-B, III-B, V-B).

With the assumption of control of public safety functions by the State Law Enforcement Division (SLED) and the implementation of procedures to report every case of patient injury or death, every incident of assault or threat of a patient or staff and any other unusual occurrence, immediate, full review is made and action taken. In addition to SLED investigations, reports are provided to the Ombudsman in my office, to the State Commissioner of Mental Health for administrative or disciplinary action and to the Solicitor for any appropriate legal action including criminal prosecution. The programmatic and staff changes made by the hospital, in combination with this reporting and review system, have greatly increased the assurance of patient safety.

Restraint and Seclusion: The new hospital Superintendent implemented a very restrictive policy governing the use of restraint and seclusion in May, 1984 (Attachment VIII-1). This policy, which is more conservative than generally accepted professional practice, requires a physician to give a written order for restraining or secluding a patient. The physician must physically be present on the treatment unit and assess the patient within one hour of a patient being restrained or secluded. Further, patients being restrained or secluded must be released within two and 24 hours respectively unless a physician again assesses the patient and writes another order justifying another two hours maximum of restraint or 24 hours maximum of seclusion (Section VIII).

The policy authorizes licensed nursing personnel to release a patient from seclusion or restraint anytime the patient's behavior warrants release. In addition, strict reporting requirements result in the Superintendent and administrative staff being informed daily of every use of seclusion or restraint. Based upon these daily reports as well as the absence of any allegations by patients, staff or families, it is safe to say that there have been no violations of the policy since it was instituted.

Significantly, the past patterns of lengthy seclusion have been replaced by brief and more appropriate periods of utilization. The use of restraints have also been markedly curtailed. The ability of the specialized treatment units to provide activities and treatment programs appropriate to each individual patient has decreased the incidents of disruptive or aggressive behavior and resulted in alternate means of dealing with such behavior when it occurs. Similarly, the frequent use of lockdowns as a means of inmate control on the forensic unit, a concern of Justice's psychiatric consultants, has been rectified. With the enhancement of staff and new management structure, such practices are no longer needed or utilized.

In the November 23, 1984 letter, five general areas of minimum remedial measures were suggested. The plans formulated by the State of South Carolina and detailed herein are appropriate and specific in addressing those measures prior to the end of calendar year 1985. They include:

1. Sufficient numbers of qualified psychiatrists and other qualified, trained professional and direct care staff will be hired by the end of 1985 to ensure, on a continuing basis, that patients are provided with adequate medical care and are not subjected to unreasonable risks to their personal safety.

2. Systems will be developed by the end of 1985 through which the appropriateness and safety of patient medical care, including psychopharmacological treatment, can be monitored to include development and enforcement of more stringent recordkeeping, physician review and approval of assessments and decisions relating to medical care made by non-physician staff, improved recording of complete and detailed background information and clinical observations relative to the medical care of patients and improved patient records detailing the course of treatment anticipated and followed, including individual treatment goals. Appropriate equipment to meet necessary medical emergency needs has been obtained and related staff training conducted.

3. Guidelines for the appropriate use of seclusion and restraint have been developed and implemented and are proving effective in accomplishing the desired results.

4. Treatment programs necessary to promote patient safety and to keep patients free from undue bodily restraint, including seclusion, have been developed and implemented and will be further improved prior to the end of 1985.

5. Measures adequate to assure staff compliance with hospital policies, protocols, and standards of job performance and behavior related to all areas of concern have been developed and implemented and will be further improved prior to the end of 1985.

As noted in the November 23, 1984 letter, many of the findings and recommendations came as no surprise to officials of the Department of Mental Health or the State. Thus, the planning and implementation were well under way by the time the report arrived and are now nearing completion with the assistance of all entities of State government. The State Legislature is acting to provide the funding and other support needed to fully institute the changes while other entities are working together to ensure implementation as rapidly as possible.

I believe, therefore, that you will concur that such violations of the constitutional rights of patients at South Carolina State Hospital as may have been found in January 1984, could not now be characterized as a continuing "pattern or practice of resistance to the full enjoyment of such (patient) rights. . ." by the hospital, 42 U.S.C. 1997a. Nor could it be said that reasonable efforts at voluntary correction have not succeeded, 42 U.S.C. 1997b(a)(2)(B); or that reasonable time to complete such efforts has elapsed, 42 U.S.C. 1997b (a)(2)(C). Certainly, you may be assured that the State will continue to cooperate fully with the Department of Justice in monitoring the Remedial Action Plan until all of the recommended actions are implemented to their satisfaction.

I will appreciate your assistance as we continue to work with the Justice Department on this critical matter. My staff contact is Ms. Sarah Shuptrine, Director of my Division of Health and Human Services, who may be reached at 758-7886. Ms. Shuptrine and officials with the Department of Mental Health and the Attorney General's Office are available to assist you as we work together to resolve this issue.

Yours sincerely,

Dick Riley

Richard W. Riley

RWR:jn

Senator Weicker. Thank you, Senator Thurmond. Senator Stafford.

Senator Stafford. Thank you very much, Mr. Chairman. I do have a brief statement, but I will ask unanimous consent that it appear in the record as if read and simply say at this point that since my early career in the Senate I have been interested in the difficulties experienced by handicapped children and handicapped adults for that matter.

Back in 1975 I joined with our then colleague, Senator Jennings Randolph, who was then chairman of the Handicapped Subcommittee, in cosponsoring Public Law 94-142, which we think did make a significant difference in the opportunity of handicapped people to have an equal educational opportunity with other people who live in this country.

I think that this hearing, for which I congratulate you, Senator Weicker, in holding, will expose some of the evidence that will make it possible for this subcommittee, the full committee, and the Senate to consider legislation which could make a difference in the way institutions of the type we have been listening to be described this morning are handled in the future.

So I hope out of all of the eloquent testimony we are hearing we can make a difference for the kind of people that have been victimized in the future. I would join with my colleagues who are here in a really urgent endeavor to try and get that done. Thank you, Mr. Chairman.

[The prepared statement of Senator Stafford follows:]

ROBERT T. STAFFORD
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[illegible]
[illegible]

United States Senate
WASHINGTON, D.C. 20510

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STATEMENT BY SENATOR ROBERT T. STAFFORD

HEARING ON CARE AND ADVOCACY FOR MENTALLY DISABLED PEOPLE IN INSTITUTIONS

APRIL 1, 1985

WE ARE HERE TODAY TO CONSIDER AN EMOTIONALLY CHARGED SUBJECT - INSTITUTIONAL CARE FOR THIS SOCIETY'S MOST VULNERABLE MEMBERS. IT IS NOT A SUBJECT THAT IS NEW TO ANY OF US. CONGRESS HAS MADE REPEATED ATTEMPTS TO GUARANTEE THE RIGHTS OF MENTALLY DISABLED INDIVIDUALS. BUT IT IS CLEAR THOSE EFFORTS HAVE BEEN INADEQUATE, AS RECENT CONGRESSIONAL INVESTIGATIONS AND MEDIA REPORTS CONFIRM. I AM SADDENED AND SOMEWHAT DISMAYED BY THE NEED TO REVISIT THIS SUBJECT ONCE AGAIN. BUT, INDEED, WE MUST.

ON NOVEMBER 17, 1983 WE HEARD ASSISTANT ATTORNEY GENERAL WILLIAM BRADFORD REYNOLDS TRY TO DEFEND CURRENT FEDERAL EFFORTS TO PROTECT INSTITUTIONALIZED PEOPLE. WE LATER HEARD FROM HEALTH AND HUMAN SERVICES SECRETARY, MARGARET HECKLER, WHO TOLD US ABOUT CONDITIONS OF ABUSE AND NEGLECT IN OUR NATIONS INSTITUTIONS, MORE EGREGIOUS THAN THOSE DESCRIBED IN THE COMMITTEE'S OWN INVESTIGATIVE REPORT.

TODAY WE WILL HEAR FROM INDIVIDUALS TOUCHED BY THIS TRAGEDY - FAMILIES WHO HAVE ENTRUSTED THEIR CHILDREN TO PUBLIC CARE AND BEEN SADLY DISAPPOINTED; FROM RESIDENTS WHO LIVED IN PUBLIC FACILITIES FOR 30 YEARS, AND NOW LIVE AND WORK IN COMMUNITY SETTINGS; AND FROM EMPLOYEES AND ADMINISTRATORS CHARGED WITH PROVIDING DIRECT CARE TO THIS DEPENDENT POPULATION.

THIS MORNING SENATOR WEICKER HAS RELEASED A SECOND INVESTIGATIVE REPORT. IT IS EVEN BROADER AND MORE DAMNING THAN THE FIRST IN THE HORRORS IT CHRONICLES. ITS CONCLUSIONS DEMAND FEDERAL ACTION. FEDERAL POLICY AND REGULATION ARE WOEFULLY OUT OF STEP WITH PROFESSIONAL KNOWLEDGE ABOUT HOW TO BEST DELIVER SERVICES TO MENTALLY ILL AND MENTALLY RETARDED PEOPLE. WE USE INSTITUTIONAL CARE IN THIS COUNTRY BECAUSE FAMILIES AND COMMUNITIES HAVE FEW, IF ANY, ALTERNATIVES.

SADLY, INSTITUTIONAL LIVING DENIES RESIDENTS BASIC RIGHTS OF MOVEMENT, OF PRIVACY, AND OFTEN OF HEALTH AND SAFETY.

IN 1975 THE CONGRESS ENACTED THE EDUCATION FOR HANDICAPPED CHILDREN ACT, PL94-142. THIS LAW REQUIRES THAT WE PROVIDE A FREE AND APPROPRIATE EDUCATION IN THE LEAST RESTRICTIVE ENVIRONMENT, FOR EVERY ONE OF OUR NATION'S HANDICAPPED SCHOOL CHILDREN. IT IS TIME WE AFFORD THOSE SAME OPPORTUNITIES TO ADULT MENTALLY DISABLED PEOPLE WHO WOULD RATHER LIVE AND RECEIVE SERVICES IN THEIR LOCAL COMMUNITIES, THAN IN A LARGE, PUBLIC INSTITUTION. A FEDERAL POLICY THAT FORCES RESIDENTS TO LIVE IN INSTITUTIONAL SETTINGS AS THE PRICE OF RECEIVING VITAL FINANCIAL SUPPORT, IS, IN THIS SENATOR'S VIEW, AN UNACCEPTABLE ABRIDGMENT OF THE CIVIL LIBERTIES OF HANDICAPPED CITIZENS.

IN CLOSING, I WOULD LIKE TO THANK SENATOR WEICKER FOR HIS LEADERSHIP IN CONDUCTING THESE HEARINGS. I WOULD ALSO LIKE TO EXPRESS MY PERSONAL THANKS TO THE MANY WITNESSES WHO HAVE TRAVELLED HERE TO TESTIFY. THERE ARE NO EASY SOLUTIONS FOR THE PROBLEMS WE WILL BE DISCUSSING. YOUR TESTIMONY WILL BE INVALUABLE TO US TODAY AND IN THE FUTURE AS WE ADDRESS THIS CRISIS IN INSTITUTIONAL CARE.

Senator **Weicker**. Thank you, Senator Stafford. I think it should be pointed out that probably no man in the Senate has been of such great assistance in this entire area as has Senator Stafford on the authorizing committee. I greatly appreciate his past help and his present assistance.

I have some questions for the panel that I would like to get into now. Please answer in any way that you care to.

You are, obviously, parents who are very concerned about your children. You take an active interest in their care and treatment. There are probably other residents, of Fort Worth State School whose parents are unable to be as actively involved in their children's care as you are.

Who monitors the care and treatment of those residents? Who advocates for their rights?

Mr. **Savidge**. Senator, I do not believe anyone really does. There are some national organizations such as the Association of Retarded Citizens who do lobby for the clients in State hospitals and institutions, but I do not believe there is any organization or individual that would really get to the heart of the problem, and that is to go to the institution and find out what happened with that client, and if necessary go to court. I do not think they do that.

First of all, one of the problems is how do you know you have a problem. State schools operate as a secret society in my own view and from my experience with them. They operate with the idea that, first of all, they will tell you nothing. If you ask a question they will give you misinformation, disinformation. If you persist they are going to lie to you. I have had that happen just this last week.

No one knows what the rights of a parent are of a child in a State institution. I have had medical problems, serious ones; to this day I do not know what my obligation is, what authority I have. Can I take that child away from under the care of the doctors at the institution? If I do that, have I forfeited the Medicaid payment of those bills? When am I to be called if there is a problem and how serious must it be? I do not know that.

I think, third, no mechanism exists that parents can utilize. Now, in Fort Worth they have a public responsibility committee which is appointed with local people on it. But it reports back to the administration of Fort Worth State School. I went through that process, and I got a nice letter back saying they would look into the problem originally 4 years ago.

Senator **Weicker**. Do both of you find, Mr. Cockerham and Mr. Savidge, do you find that the institution tried to cover up the difficulties that exist in those institutions?

Mr. **Cockerham**. I most definitely feel they try to cover up certain activities. Every unit at the State facility is run like a little bastion of its own and they like to keep everything within. I do not think the superintendent himself is responsible for trying to cover up as much as each unit in itself.

They try to cover up and keep everything within each area and make the records look as clean as possible.

Mr. **Ferleger**. Senator Weicker, let me answer that with a specific instance. One person who helped actually bring some of the

Texans and Philadelphians in this room together here is Reese Jones, head of the Brums Foundation, who is sitting behind me.

His son, Mark Jones, was drowned at the Fort Worth State School in 1981. A lawsuit eventuated. The State had in its possession and it resisted giving to the plaintiffs or the court their internal report showing how Mark Jones died.

It was only after a struggle and a court order from Judge William Wayne Justice, a courageous judge in Texas, that the State was forced to hand over finally their own truthful report on what had happened, and 3 days later, Senator Wiecker, they settled the case for $250,000.

But had the parents simply wanted the truth about what was happening, it was unavailable except after a struggle through the courts. So imagine the plight of parents who do not have a judge behind them trying to find out what has really happened and imagine the plight of the protection and the advocacy agencies that Senator Stafford and you know are created under the DD Act trying to do the job with the measly, insufficient budget that the Congress has so far allocated to them.

Senator **Weicker**. Yes. I think one thing that should be pointed out—and you correct me if I am wrong because you are far more the expert in these areas than I am; the protection and the advocacy actually only extends to the mentally retarded. There is none for the mentally ill.

Mr. **Ferleger**. There is nothing and when the Congress was asked back when Rosslyn Carter chaired the Commission on Mental Health to create even a bill of rights for the mentally ill, the Congress simply adopted a set of suggestions to the States. When the Congress did, as Senator Stafford wrote it, create a bill of rights for the retarded, the U.S. Supreme Court in my case, unfortunately, decided that the Congress did not mean what it said in the statute, in the DD Act.

Senator **Weicker**. I have one question and then I am going to turn to Senator Simon for questions. Incidentally, Mr. Cockerham, staff indicates to me that Chris has had severe hearing loss as a result of the beatings he received?

Mr. **Cockerham**. He has a hearing loss since this has happened. He has always had some problems with his ears, but the hearing loss has been more since this happened. I have taken him to a specialist.

Well, I first asked the State to look into it. They had a hearing test and said there was no problem. I took him to a specialist and they said he had severe hearing loss, and since that period of time his speech has gone down to where he will not speak out loud. It will not come out. Apparently, he thinks he is talking at a volume and he is not.

Senator **Weicker**. I get back to the point that I tried to make at the outset in my informal opening remarks. You used a very good term; these are first-class citizens. Indeed, they should be a little bit more in the sense that they are many different people suffering from many illnesses and we certainly give them our special care. By what legal process, just out of curiosity, do we have to pass laws giving to them what all of us have? Where in the process do they lose their first-class citizenship? That is what I do not understand.

Mr. **Ferleger**. Well, that is a good question and it is curious that we have to be here talking about granting people the right to be free.

Senator **Weicker**. Again, I am going to hammer home again and again during the hearings; these are not people who have been convicted of anything.

Mr. **Ferleger**. Well, and not only that, Senator Weicker, you are wrong in one respect. People who are retarded do not have a disease. They have a condition, a status, the same as being black, or white, or smart, or not so smart. And people who are mentally ill do have difficulties, but the Congress should not have to be involved.

And what has happened and the reason we are here is the States themselves which run these institutions have reason to turn their back on the abuses. The State legislatures do not know often what is happening, and their laws are just as routinely ignored as the Federal laws.

The executive branch of the U.S. Government is ignoring what is happening, and the Supreme Court of the United States, although they have held that people have a right to be protected from harm, have not held that people have a right to get decent care, habilitative care in institutions.

So, we wind up almost that the Senate is a last resort, not because we want to be here. We would rather be in our States having the States protect our rights, but that is just not happening.

Senator **Stafford**. Mr. Chairman, did we not have a somewhat similar situation with respect to handicapped children and their education until we passed 94-142?

Mr. **Ferleger**. That is right. As you know, but some other people might not know, 94-142 not only allowed families to keep their children from going to institutions, but it has allowed many children living in institutions to move back to the community.

And the States did—and some of them still turn their back on even children, let alone adults. And there is another thing that is happening, Senator, that while we are at it I wish you would fix in the law. And that is this: Many States have ignored the intent of 94-142 by providing what they call special education in the institutions themselves.

In Texas, the school district is the institution. And they have people literally in a corner in the ward, and that is what they are calling free, appropriate public education under 94-142.

Senator **Stafford**. Well, thank you. The point I was trying to make was that 94-142 did make a difference nationally, and that I am sure under Senator Weicker's leadership we can find a way to legislate that will make a difference in the situation we are having described for us this morning.

Mr. **Ferleger**. 94-142 has had a tremendous effect. Jonathan Savidge is leaving the State school every day to go out to a public school. Chris Cockerham is in a public school program and but for 94-142 that would not have happened.

Senator **Stafford**. Thank you.

Senator **Weicker**. Senator Simon.

Senator SIMON. Yes. First of all, on the 94-142, I want to join the chairman in commending Senator Stafford for his leadership in that.

It seems to me that that in some way—and I do not know what it is, and we look for your leadership on this, Mr. Chairman—somehow there has to be a mechanism, whether it is through the Justice Department or how, to provide greater protection.

The courts have done it for our prisoners. It does mean that every prisoner is getting the kind of protection that he or she should have; we just saw a tragic story in the Washington Post about an 11-year-old in prison and how that 11-year-old was abused.

But at least, there is a legal framework, and my counties in Illinois are now trying to do a better job for prisoners. Somehow we have to maintain or move toward some kind of a similar set of standards, it seems to me, for those in institutions for the retarded.

One of the basic questions was asked by the chairman, and I think the answer is obvious; what about the Chrisses and the Jonathans who do not have people to speak for them? And I remember visiting the Lincoln School for the Retarded in Illinois many years ago when I was in the legislature and asking the superintendent, "Do the majority of your patients have relatives who visit with them and pay attention to them and he said, 'No.' "

And my assumption is that that is probably pretty much the case yet today. But one point, you both alluded to the doctors and the care. In Illinois we have had a dual set of standards for recognizing physicians. In other words, we have a set of standards for physicians who work with the general public. We have a different set of standards, unless it has changed just recently—and I am not sure—but we have had a different set of standards for those that work in the institutions for the mentally ill and the mentally retarded.

Do you have a similar situation to that in Texas, do you know?

Mr. FERLEGER. In many States—and I believe Texas is one of them—have different procedures. Sometimes, Senator, it is a special license, sort of a temporary or special license where you can get admitted to work in an institution but you could not practice on that license in the community.

But there is a more——

Senator SIMON. But if I may interrupt, that special license is in fact a second-class license.

Mr. FERLEGER. That is correct, someone who cannot meet the first standards.

Senator SIMON. That is right. So you get second-class care in those institutions.

Mr. FERLEGER. Well, and the more insidious problem is that institutional care has the same low value that the rights of people in institutions have, institutional medical care. So that the best doctors often avoid working in institutions and the only way they can get medical care at all is to get the bottom of the barrel instead of the top of the barrel. And that has been a very serious problem across the country.

Senator SIMON. Then one final observation; that is the area of research. It seems to me there is another area where at the Federal level we could do more, both in a preventive way and to tap this resource that is there. I always remember visiting a place called Beverly Farms in Godfrey, IL. It is a privately run facility. And, incidentally, one of the other things that strikes me as a visit facilities for the retarded is the dramatic difference between the public institutions and the private institutions that most people cannot afford.

And it shows we have a long way to go to be doing what we ought to be doing.

But I remember visiting this Beverly Farms, and Dr. Smith, who is now dead, was the superintendent taking me around. They had this one—they called him a boy but he was about 35 years old—he said give him a math question. And I gave him, you know, two times four or something like that. He said no, no, give him a hard one. And I do not remember what it was, but it was something like 69 times 332 and he came out with an answer like that.

And I quickly took out a piece of paper and calculated it and it was right. Now, somehow he is regarded by our society as retarded. But there is a potential there that we have not tapped yet. And I think that is true for a lot of the retarded of this Nation.

I do not know when and how we have that breakthrough, but I think the Federal Government ought to be part of the research on that breakthrough.

Mr. **Ferleger**. And what you point out is the benefits to us of our contact with people with handicaps. And we learn from being with Chris Cockerham and Jonathan Savidge. Students who are in schools with handicapped peers learn too. It is not just for the benefit of people with retardation that we are here; it is really for the benefit of all of us.

Senator **Simon**. I could not agree more. Thank you, Mr. Chairman.

Senator **Weicker**. I understand this Fort Worth school is certified and it receives Medicaid funds. In fact, approximately $8.5 million this year. To your knowledge, has there been any Federal investigations by the Justice Department or HHS as a result of these situations described here?

Mr. **Ferleger**. No. In August 1984, however, the State Medicaid licensing agency found Fort Worth State School in violation of ICFMR regulations and gave them a certain amount of time not to fix up the violation, but simply to file a plan promising to fix them up. And the big problem with HCFA, the Health Care Financing Administration, and the way HHS administers the Medicaid program is that States get by with violations in two important ways: One, by simply making promises so that the next year or 69 days later if they have not fulfilled their promise they make a few more.

And they get by in another way: Medicaid forbids people to live in dormitory style living, but at Denton State School and Fort Worth and other places in Texas you walk in and find an overcrowded, huge ward with bed and cribs piled up one next to the other. And how do they do it? Well, they write into the individual habilitation plan this person needs for their habilitation to be in an overcrowded dormitory. And Medicaid allows, according to the people I have spoken to, State administrators, Medicaid allows that loophole, and that is just an outrage.

Senator **Weicker**. Mr. Savidge, your testimony states that Jonathan was injured 124 times since his admission to the school and that you were informed of only 25 of those injuries. What was the school's explanation for the other 99?

Mr. **Savidge**. Well, Senator Weicker, I have never received an explanation. That fact that Jonathan had been injured 124 times came to me as I was sitting on a witness stand in a Federal court last year at about this time. And Mr. Ferleger kept handing me one piece of paper after another. Do you know anything about this? He would read another one. Have you heard of this? I sat there for the longest period of time. I said I have never heard of any of them.

Senator **Weicker**. Would you like to account as far as your child is concerned, Mr. Cockerham?

Mr. **Cockerham**. Well, I cannot relate any serious abuse like the last one we found other than the one time they never did notify us, and when I questioned the fact of a large cut on his back, he ran into a sliding glass door or something to that effect.

Senator **Weicker**. But how does a child end up with this kind of a beating on a one-time basis?

Mr. **Cockerham**. Oh, I do not feel it was a one-time basis. This severe on him, that is the worst I have ever seen. Every time you go out and pick a child up they have bruises, cuts on them, and everything else. But you have to excuse a certain amount of it because when Chris was first admitted to the Fort Worth State School he was not aggressive in any manner whatsoever. Within 3 months he was, though, from having to fend for himself because the attendants, they throw them in a room, the day room they call it, and if you want something you fight for it. They learn to live that way.

Mr. **Savidge**. Senator Weicker, the night that Chris Cockerham was severely beaten we have reason to believe there were three boys. Mr. Jones and I became aware of that and it is not just an isolated incident.

Senator **Weicker**. There were three boys who were beaten?

Mr. **Savidge**. Severely beaten the same particular night.

Mr. **Ferleger**. The name of one of them is Chris Money and the State has admitted that somebody else was beaten at the same time, but apparently—and you referred to it before—that family may not exist. This other resident apparently has no advocates because nobody stepped forward to complain for him.

Mr. **Cockerham**. The school played down the incident that happened to Chris. They act like there was not anything really that severe wrong with him. With the report that we received from them if we had lived 500 miles away we probably would have never gone and checked this out.

Senator **Weicker**. When were these pictures taken?

Mr. **Cockerham**. The day after the incident happened.

Mr. **Ferleger**. February 28, 1984.

Senator **Weicker**. And the State said that they did not consider that anything had happened to him?

Mr. **Ferleger**. It is worse than that. The result of their abuse investigation by the abuse investigation committee of Fort Worth State School was "no confirmed abuse." And the reason they gave later when obviously something had happened is that if they cannot identify the perpetrators specifically they record that in their statistics as no confirmed abuse.

So that when we see statistics—and I have the records in my office—about dozens of cases of no confirmed abuse what it turns out to be is either they cannot identify the perpetrator or they think it is a management problem. One person at Austin State School was left unattended with a thermometer in his mouth and bit down, broke the thermometer, swallowed the bulb, and that was recorded as no neglect.

Another resident was shaken and hit by an attendant; the attendant said to the resident, I will kill you, I will kill you at Austin State School within the past year, and they considered that to be not serious enough to warrant the finding of abuse.

Senator WEICKER. In terms of abuse and neglect by the attendants, do you feel that is inherent in the character of the attendants or in the lack of training and the lack of adequate numbers of attendants? In other words, what is the problem here? Do we just get the bottom of the barrel for attendants, or indeed are these people so extended in terms of lack of personnel and the lack of training that they cannot do their jobs? I would like to hear everybody on that.

Mr. FERLEGER. Let me start it. It is not the character of the attendants. I respect and care for people who work in institutions for people with disabilities. The problems are a couple, the lack of training. The person who was with Mark Jones when he drowned in a bathtub at Fort Worth State School had never received CPR resuscitation training, for example. So there is a training problem and there is a problem inherent in working in the institution. It is a dismal, depressing place to work. You do not see progress in the clients who you are caring for. And it burns people out very easily and creates a frustration level that I think results in people like Chris or Jonathan being hurt.

The remedy is to take those same good workers and put them in a normal home in a normal community and have them caring for a small number of people where they do see changes. Chris Cockerham now lives in a group home and he is doing marvelously. I mean, that is the kind of care that we need.

Jonathan Savidge, the institution says he needs a foster home. They have not given him one, but when he goes there he will do marvelously too. But it is not bad staff, and the remedy is not just pouring in more staff. The remedy is taking those good staff who are there—and they are, nearly all of them—and giving them a decent place to work just like these people who are handicapped need a decent place to live.

Mr. COCKERHAM. I feel as though there is a morale problem within the institution with the employees. I do not care if you are taking care of the handicapped or you are making automobile parts, if you do not monitor the employees and keep all of them working at the same pace efficiency is going to go down.

There are some very fine people working at the facility but they have to observe the ones that are not, that do not take care of kids, that mistreat kids, and those people are possibly promoted above them or make the same amount of money.

And the loyal, good employees that got that job to take care of kids finally have burnout and quit because they cannot keep watching what is going on and taking care of children the way that they want to and watch other people abusing them.

As it is set right now, all the abuse reports and everything you see are only the ones that have eye witnesses and people will testify against. Employees have noted that they are threatened with their cars being fire bombed or their house being set on fire by other employees if they report things that happen.

There are a lot of scared individuals that will not come forward and testify against things that are happening like this, and if they do not, there is not a report ever filed.

Senator **WEICKER**. Well, I think you make a good point because we know that, those of us that are involved, the reports are not filed. The advocacy does not take place. It took a great deal of courage on your parts to appear here today and to tell this story.

Mr. **SAVIDGE**. I think there is another problem here, too, Senator. Texas utilizes a medical model in operating State institutions. They have 800 or more employees at the Fort Worth State School. It is a large facility and I do not believe that they know how to manage it. I do not believe that they have people capable of managing that kind of employees taking care of that kind of facility and handling those special problems.

And this leads to a factor which Mr. Cockerham just touched on. There is a great deal of fear by employees at Fort Worth. One employee on one shift will never know what is happening on the previous shift or the one after it. They will not pass information along.

It is an operational mandate, I believe, that no one, as far as an employee, is to talk to another employee about anything. I talked to a gentleman yesterday who works in the infirmary. And he does not know what is happening on the shifts before him or after. There is a lot of this; there is an attitude of intimidation, and it is a system that collapses on itself, and I just think that the only rats left on a sinking ship sometimes are the sick rats.

I think we have a situation where good people will not stay in the system. They come in; I have seen some very beautiful people working with Jonathan, but they cannot stay there. As Mr. Ferleger said, the facility is not there for them to stay there and put up with what they see.

Senator **WEICKER**. Let me just conclude and ask this question again. One will have to be done verbally, the other visually. As a result of Jonathan's stay at the institution, what is the result physically on Jonathan today as compared to before he went in the institution. He is now in a wheelchair?

Mr. **SAVIDGE**. When Jonathan went into the institution he was mobile. He could walk with the aid of a walker. He had both arms and legs working. We had every hope that he would regain his balance and learn to control his hyperactivity and come home.

Today Jonathan is totally nonambulatory. He has lost the use of his right arm and leg. He has developed severe scoliosis now. I think he has paid a terrible price for the short years that he has lived there.

Senator **WEICKER**. He has. He has paid a terrible price and there is Chris's price. There is the price that is being paid for the failure of all of us to exact the same standard, if you will, of care and of love that we give to everybody.

I can only say that certainly if the sacrifices of these young people and their families and their parents do not mean anything to the Nation, then the Nation is the one that ought to be in the institution.

Because reference has been made to him, I wonder if Mr. Reese Jones is here and whether or not, Mr. Jones, there is anything that you would like to add to what has been testified to here today.

Mr. JONES. No; I am just a bystander and very interested in what is going on.

Senator WEICKER. It was your son who died?

Mr. JONES. Yes, Mark Jones at the Fort Worth State School.

Senator WEICKER. I gather that what you have tried to do in terms of a living memorial is to assist those who bring these matters to the public conscience. Am I correct on that?

Mr. JONES. Yes; I set up a foundation and filed a Federal lawsuit about his death to allow quality legal representation for institutionalized people and their civil rights.

Senator WEICKER. Well, it is a pleasure to have you here, Mr. Jones, a great pleasure.

Is there anything in conclusion? I have no further questions. Is there anything that any of you would like to say now? Please do not hesitate to speak.

Mr. SAVIDGE. Well, I would like publicly to follow along with what has just been said and thank Mr. Jones for his help with Jonathan. If it had not been for his help in all probability we would not have Mr. Ferleger here. I had nine attorneys that I tried to get to represent Jonathan in the State of Texas and they did not do it. One attorney sent back all my records and there was a little handwritten sheet of paper that came with it. I would just like to read about two sentences because it sums up a tremendous problem we all have as parents in trying to get legal representation if that is the only recourse left.

> I have a problem with damages. Judging from history paralysis will have only minimal impact on kid anyway; he probably also as a short life expectancy. Also have problem with Tort Claims Act.

He turned my case down. They will also turn the cases down if you do not have the financial backing up front, and I think somebody like Mr. Jones is doing a worthwhile service to all handicapped people.

Senator WEICKER. I am not so sure that if I do not get a better response out of the Justice Department of the United States that I am going to have to use Mr. Jones also. I have just about as much trouble as you do in getting onto these matters with our own Justice Department I say that not, I might add, facetiously, but with a great deal of anger.

Mr. COCKERHAM. Again, I would like to state that Mr. Jones has been a great aid to my wife and myself. The first night that I met Mr. Jones we went over, and I think that the reason a lot of families do not come forward is the fact that they feel as though they have the last avenue that they can possibly try in having their child in a State facility.

It is not easy to get a child in. There are people on waiting lists. It takes years and years to get them there and they are not adequately equipped to take care of them at home. Once they get them in a facility they overlook so much because I do not think that they have any rights. They have been taught that they do not have any rights.

And to recap a little bit earlier when you asked should we have to have laws enacted to safeguard the children. Yes, we do. I can go back to the first 3 hours that Chris was born. The physician that delivered him said Chris is seriously ill and he will be better off if he dies.

Now, then, when you have professional people telling you things like that from the time that you are born, you feel as though they do not have any rights and you have to enact laws to protect them.

Senator **WEICKER**. I think I know a little bit whereof you speak because when my Downs child was born I was asked whether I wanted to keep him or give him away.

Senator Stafford, any further questions?

Senator **STAFFORD**. No further questions.

Senator **WEICKER**. I have no further questions. I want to thank you all for your testimony and I would hope that the value of what you have done here today will show up as a matter of law before this year is out.

Mr. **FERLEGER**. We would like our written testimony to be included as part of the record.

Senator **WEICKER**. All of your written testimony will be included in the record in its entirety as will these photographs be included in the record.

[The photographs referred to follow:]

Senator **Weicker**. If there are any further matters that you wish to present to the committee, the record will be open for presentation of those matters to the committee. Statements of the various Senators and questions of Senators also will be included in the record, and if there are any question for response in the record I would appreciate if that would be accomplished by counsel. I thank you very much.

Mr. **Savidge**. Thank you, sir.

Senator **Weicker**. Our next panel comes to us from the State of New Jersey: Ms. Carol Sands, an attorney with the Department of Public Advocacy who has been subpoenaed here today, Mrs. Maureen Kelly, whose son James is a patient at Trenton Psychiatric Hospital, and Nurse Jenni Tolska, who is employed by the State's Division of Medical Assistance and Health Services, who has also been subpoenaed.

Our first witness is Ms. Sands. Ms. Sands, would you please stand and take the oath, please. Would you raise your right hand. Do you swear to tell the truth, the whole truth, and nothing but the truth, so help you God?

Ms. **Sands**. I do.

Senator **Weicker**. Please be seated and proceed with your testimony in whatever way you deem fit.

STATEMENT OF CAROL SANDS, ASSISTANT DEPUTY PUBLIC ADVOCATE, DEPARTMENT OF THE PUBLIC ADVOCATE, STATE OF NEW JERSEY

Ms. **Sands**. Thank you. As you know, I am an attorney for the Department of the Public Advocate of the State of New Jersey employed as assistant deputy public advocate

The Department of the Public Advocate is mandated to provide legal representation for any psychiatric hospital patient who does not have the financial ability to secure legal counsel. I represent patients at Trenton Psychiatric Hospital and other hospitals in New Jersey at weekly commitment hearings in regard to their right to freedom, to adequate treatment, and other basic civil rights.

I was subpoenaed before this committee, and I thank you for the opportunity to appear here and speak before you. I frequent the wards of these hospitals and I know many of the patients and staff well. I would respectfully like to call the attention of this committee to three problems regarding abuse and neglect in psychiatric institutions in New Jersey.

One, continuing reports of abuse at Trenton Psychiatric Hospital and other New Jersey State hospitals as well as inadequate administrative and institutional police response to the problem.

Two, excessive restrictions on the freedom of individuals in State psychiatric hospitals.

And, three, lack of treatment for patients and incarceration of these individuals without fresh air, exercise, or meaningful activity.

In the past 5 years our office has received numerous reports from Trenton Psychicatric Hospital of patient beatings, threats, and intimidation, encouragement of fights on the wards by staff, and other abuses. Concerned hospital staff contacted us several years ago and expressed fears of reprisal by other hospital employees.

Between 1980 and 1983 we sought to have an investigation of the hospital. We brought eye witness testimony by hospital staff to the attention of the hospital authorities and provided the attorney general, the local prosecutor, and hospital administration with reports. We were asked for yet more evidence.

We then presented more evidence of patient beating. Despite our continued efforts our requests for investigation were merely referred back to the hospital administration. We are not aware that any investigation was ever performed since despite our requests we received no notice of such.

Recently, we have tried to seek better investigation by institutional police of individual complaints. However, repeatedly we encountered inadequate investigation and failure to protect patients from abuse.

In Marlboro Psychiatric Hospital in New Jersey a patient recently reported to us in affidavits that she had been raped by six or seven inmates from a local prison who were working in the hospital cafeteria. The hospital police were notified the day of the incident, but they did not see to it that the young woman was medically examined. Even though it is standard procedure in New Jersey police departments to take alleged victims immediately to the designated county medical center for testing for rape, instead the hospital police requested an examination of the patient by the psychiatric hospital. The assigned doctor then refused to do the examination since he was not a gynecologist.

He further stated that since the young woman was bleeding he could not perform an exam. By failing to obtain the proper examination, the institutional police imperiled the health of the young woman and also hampered a criminal investigation.

This situation is similar to that which occurred at Trenton Psychicatric Hospital in the case of James Kelly whose mother will be providing testimony. The human services police never followed up on her report of suspected abuse even though the sergeant of police had three sworn statements from witnesses that they had seen blood on the back of her son's pajamas.

When I spoke with the sergeant he could not tell me why they did not investigate this incident or why they tried to prevent the patient's mother from seeking an exam for medical injury to her son.

In the past year our office has also received a number of reports from adolescent patients of abusive practices occurring in Trenton Psychicatric Hospital. Incidents of assault and battery, threats of bodily injury to children, and intimidation due to an atmosphere created by the use of force and punishment were alleged in affidavits by patients. The choking of an adolescent in the presence of other staff witnesses was reported and one child alleged that on repeated occasions he was dragged through the ward by his hair by a staff member.

We also received other reports of assault and threat. Some of the children were afraid to give sworn statements to us and to the police, but others gave affidavits regarding these incidents. It is now 6 months since the incidents of reported assault and choking of adolescents by staff members were reported, and the institutional police have still not issued a report on their investigation. Although we were able to have one staff member accused of choking an adolescent transferred to an area of less patient contact, we are told the police are unlikely to take further action, and other staff members accused of abuse were merely mixed up within other cottages of adolescent clients. We remain concerned about our clients' safety.

The inadequate investigation by hospital administration and hospital police has been a recurrent problem. Recently at Greystone Psychiatric Hospital the hospital police cleared a staff member of assault even though the staff member had admitted in writing both in the patient's chart and in the incident report that he had struck the patient. The patient had suffered a lump on his head and bruised and cut lip.

As in this case, the patient's complaint of abuse and in other cases families' complaints of abuse are repeatedly ignored.

In addition, at Trenton Psychiatric Hospital administration has removed the unusual incident reports of medical injury to patients from the medical records. Therefore, we have no access to them. Repeatedly we have sought to obtain these medical records in situations of reported abuse.

A month ago I asked to have access and was denied, and again even within the past week I was denied access to the reports in cases I had where clients were abused. The problem of a lack of patient protection from abuse remains, creating a situation of danger for our clients.

In the adolescent unit in the past year or more I have rarely seen children play outside of the hospital wards or be exposed to the fresh air. My clients have continually told me about their lack of exercise, the inability to use their energies, to run, to use the gymnasium, and especially to be outdoors. The prison like conditions in the adolescent units seem to have worsened in the last year.

Even though a majority of these children are simply awaiting placement in the community and schools for special education or other settings, they are locked in 24 hours a day with rare exceptions unless they are in school. While they are locked up on the unit adolescents stated there is a great degree of control by staff on the few activities they are allowed. They even have to rely on staff to unlock a door to be able to use the bathroom or to use a water fountain. If it is inconvenient for staff, therefore, they have to undergo significant discomfort.

Verbal abuse is allegedly commonly used by staff. Because the children are so often locked up without fresh air or activity, they often get in trouble for small infractions or for aggressive play when they are trying to seek diversion on a locked ward.

They often feel frustration and humiliation at their confinement. As a result almost every day a child seems to be restrained to a bed, put in seclusion, or medicated by forcible injection, the adolescents reported. It is noteworthy that the Medicaid 1984 periodic medical review of the adolescent unit made a special comment on the use of mechanical restraints and seclusion.

The team stated that review of the records showed that restraints were used too frequently and other alternatives of modifying behavior were not being observed They also stated that efforts did not appear to be made to differentiate between normal adoescent behavior and abnormal or extreme behavior when restraints and seclusion were used to control patients.

They concluded "it is strongly recommended by the PMR team that mechanical restraints be used in a more judicious manner."

With the absence of meaningful activities and treatment in the past the privilege to use the attractive, park like grounds of the hospital was a main form of therapy. Patients who achieved a certain level of good behavior would be allowed passes to go outside, to go to the hospital canteen, to have coffee, and to socialize with others or buy personal items they needed.

Many patients had ground passes for years. Therefore staff at the hospital and patients alike were alarmed when in December 1988 the grounds pass of every patient in the hospital was suddenly revoked because of the escape of one patient.

People who had passes for 10 years were suddenly locked up. Open ward programs were discontinued and still not been reopened. Therapy and classes that occurred off the wards were permanently closed because no patients were allowed to go to them.

This situation continued throughout the spring and summer for a period of 8 months. The patients missed experiencing two entire seasons of the year. Seven months after that one escape only 10 patients in the hospital were ever allowed outside. For 8 months none of my clients had gotten any fresh air or exercise, and I was unable to advocate for patients to go to therapies such as vocational rehabilitation or other programs because staff were afraid that if they referred patients to go to therapies they would be disciplined for allowing them to go outside.

Patients were even rebuked on the wards for going near the window to try to get fresh air. Staff told us that patients' mental conditions in the unit were worsening. Unsuccessful in negotiations to alleviate this problem, our office had to bring suit. Although improvements were made the hospital grounds are still relatively empty at this time.

In Marlboro Hospital the situation of lockup continue to be as severe as it had been at Trenton Psychiatric Hospital before we brought suit. There due to an even greater population of patients the wards are overcrowded and unclean. There are insufficient chairs for patients to sit on, and a lack of space and fresh air within the wards causing a situation of dangerous tension in the hospital.

One of the most open of state hospital programs, Marlboro is now the most prison like.

When the official body for accreditation of Trenton Psychiatric Hospital decided to inspect to see if the hospital met requirements for Federal funding, I saw for the first time activities being conducted out on the wards involving all the patients in creative arts, crafts, and other rehabilitative therapies.

One day during such an inspection I observed a ward of young male patients busily occupied at a table assembling very handsome plywood models of airplanes, cars, and other vehicles. That was the only time I ever saw that activity. My other colleagues observed that staff were taking patients out to play football with them using equipment we had never seen before or since.

We saw patients taken on buses to go for rides and picnics. When the accrediting agency left these activities disappeared, too.

Staff members at Trenton Psychiatric Hospital have complained to me about increasingly cumbersome record keeping for accreditation. So much writing of patient treatment plans and records is required by administration that staff say they have no time to spend with patients. This situation was reported in the Trenton Times article of July 2, 1984. One staff member was quoted as saying, "There's a lot of treatment planning but very little treatment." Another therapist explained, "Somehow we've been bound up in a paperwork horror show so that 90 percent of our time is spent in documentation."

Since I have been working with hospital patients the treatment plan for each patient has increased from three pages to nine pages even though treatment has not increased. Indeed, recently the hospital administration ordered the layoffs of several therapists, cutting many patients off in the middle of therapy with no substitute. Most of the day the majority of patients still lie or sit on the floor on the ward or on chairs.

Many of them desire activities such as vocational rehabilitation to improve their working skills, but can get no one to refer them to these programs. Because some of the patients are dependent upon training to have a realistic opportunity to leave the hospital and live in the community, the lack of treatment is one of the most crucial issues for them. Without it many of them live without hope of ever living in the community again or leaving the hospital ward.

The statutory patients' bill of rights in New Jersey, which mandates the patient's right to adequate treatment, civil liberties, to fresh air and to other human rights, is still very far from realization. Instead, the reality for many patients in these hospitals is only the four walls of the ward that they live in without knowledge of when, if ever, they will be able to be free. Thank you.

[The prepared statement of Ms. Sands and additional material supplied for the record follow:]

CAROL SANDS, ATTORNEY
TRENTON, NEW JERSEY
TESTIMONY BEFORE THE U.S. SENATE SUBCOMMITTEE ON THE HANDICAPPED

INTRODUCTION: I am an attorney employed as Assistant Deputy Public Advocate, in the Department of the Public Advocate of the State of New Jersey. The Department of the Public Advocate was created by the New Jersey Legislature in 1974 as a Cabinet level state agency broadly responsible for seeking the enforcement of the public interest. The Division of Mental Health Advocacy is mandated to provide legal representation for any psychiatric hospital admittee who does not have the present financial ability to secure competent legal counsel, and to act on behalf of hospital patients as a class on an issue of general legal interest to them. In the employ of the Mercer field office of our division, I have represented patients at Trenton Psychiatric Hospital and other hospitals in the region of central New Jersey at weekly commitment hearings and in regard to their right to liberty, to adequate treatment and other basic civil rights. I am frequently present on the wards of this hospital and know many of the patients and staff. I was subpoenaed before this committee because testimony was being taken regarding abuse and neglect at institutions where our division represents patients. I have represented James Kelly, whose mother also presented testimony. I would like to discuss three issues regarding abuse and neglect in psychiatric institutions in New Jersey:

1. Continuing reports of abuse at Trenton Psychiatric Hospital and other New Jersey state psychiatric hospitals and inadequate administrative and police response to the problem.

2. Excessive restrictions on living conditions and access to outdoors imposed on individuals in state hospitals.

3. Absence of programming for patients, resulting in warehousing of clients and deprivation of the right to liberty, to exercise, to have meaningful activity and to needed treatment.

I will touch on the testimony presented in affidavits and other documentation provided to the committee.

CONDITIONS OF ABUSE AT TRENTON PSYCHIATRIC HOSPITAL

Our division has a history of extensive effort to seek investigation of conditions of institutional abuse. For a period of over two years, between 1980 and 1983, we received a series of reports from Trenton Psychiatric Hospital that staff were ignoring major incidents on the units such as altercations between patients; that staff were striking patients with keys, punishing patients with threats of seclusion and forcible medication and ignoring patients in situations of posible danger. Hospital administration at the highest levels were repeatedly addressed with pleas to investigate. The Attorney General was requested to do an undercover investigation. The Attorney General referred the matter back to the State agency which administers the hospital. Former hospital staff members presented eyewitness testimony of abuse to the hospital administration and to other agencies at meetings. After many meetings and letters exchanged, we were able to obtain only a recommendation from the Attorney General that the hospital perform its own internal investigation. Although we believe that an investigation may have been performed, we were never informed of the results, despite the fact that we had initially requested the investigation.

INADEQUACY OF INVESTIGATION BY HOSPITAL ADMINISTRATION AND POLICE AT NEW JERSEY HOSPITALS

In the individual case, as well as with ongoing abuse, we have been unable to secure adequate investigation by hospital administration and by agencies such as the institutional police which is subsumed under the Department of Human Services. Without such investigation we have been unable to extend significant protection to our clients from abuse.

An example of this problem occurred in Greystone Park psychiatric hospital in New Jersey where we had a client complaining of assault by a staff member at the hospital. Our staff visited and observed that the client had a lump on his head and a bruised lip. Although the staff member had admitted in writing both in the patient's records and the medical chart that he struck the patient, the staff member was still completely cleared of the incident by the hospital administration and the institutional police. They denied our client the right to file a complaint against the staff person. Only when we insisted upon action, going to the Chief of Police and pointing out the evidence , was disciplinary action taken against the staff member, and he was fired. Thus had it not been for our intervention, a staff member who had admitted striking a patient would have been allowed to continue working at the hospital.

In another case, at Marlboro Psychiatric Hospital, a third state institution in New Jersey, a female patient reported she had been raped by several inmates working in a prison project in the hospital cafeteria. The institutional police were notified the day of the incident. Whereas in every county in New Jersey, the major police departments have standard operating procedures whereby they immediately transport the alleged victim to the appropriate medical center for an examination for trauma due to rape, and lab testing according to regular police procedures, the institutional police do not. In this case, they instead asked the psychiatric hospital to provide an examination, and a doctor assigned refused to do the examination because he was not a gynecologist. He further stated that since the young woman was bleeding, he could not perform an exam. At that point, the institutional police failed to take her to a general hspital in the community where a gynecological examination and appropriate laboratory testing could be performed. By their failure to take this next step, the institutional police greatly hampered the criminal investigation.

This is similar to the situation that occurred at Trenton Psychiatric Hospital in the case of James Kelly, regarding whom you have received testimony. Before witnesses were even interviewed, the institutional police tried to compel the complainant, Mrs. Kelly to leave the ward. She was not permitted to seek a physical examination for possible abuse to her son, at the appropriate medical center. Although as his legal guardian she had been granted the right to take him off the ward for an extended period that evening, the hospital staff, administration and institutional police would not permit her off the ward with her son after she reported the suspected abuse, so that she could go to the local hospital. The Human Services police did not follow up the report, although the Sergeant of Police told me that he had three sworn statements by witnesses of blood on the back of the patient's pajamas. The Seargent could not explain why the police did not follow up this report or why they tried to prevent the patient's mother from seeking an exam for medical injury to him. You can imagine the feelings of the mother who is told by three people that her son has been seen with blood on his clothing, but is not allowed to take him for a medical examination, despite the fact that she is a registered nurse and is his legal guardian.

ABUSE AT ADOLESCENT UNIT OF TRENTON PSYCHIATRIC HOSPITAL

In the past year a number of reports were received by our office from patients alleging abusive practices in the adolescent services unit of Trenton Psychiatric Hospital. Patients alleged incidents of assault and battery, threats of bodily injury to children, and intimidation due to an atmosphere created by the use of force and punishment. A report prepared by our staff summarized the numerous allegations of excessive force, including the choking of one adolescent in the presence of other staff witnesses, repeated occasions where one child was dragged through the ward by his hair by a staff member, and other reports of assaults and threats. Some of these were documented in affidavits, while other children were afraid to give sworn statements to us and to the police.

With respect to these alleged abuses there was a similar lack of response by police and administration. Six months since the incidents of reported assault and choking of patients by a staff member, the institutional police has still not issued a report. Although we were able to have the staff member transferred to an area of less patient contact, further action is unlikely to be taken by the police, they have told us. The

Unit Administrator shifted other staff accused of abuse to different areas of the unit, at our suggestion, but we remain concerned about our clients safety.

The inadequate investigation by hospital administration and by institutional police has been a recurrent problem. Failure to honor patient and families' complaints of abuse has also been a continuing situation. In some cases we have encountered simply a refusal to investigate at all. In addition the hospital administration has denied us the crucial tools for investigating abuse, having removed the incident reports from the charts of patients at Trenton Psychiatric Hospital and denied us access. The incident reports are standard hospital records of any unusual incident such as patient injury, altercations between patients or between patients and staff. For a substantial period of time, Trenton Psychiatric Hospital has removed them from the patients' charts where they used to be, although they are still kept there at other hospitals. Without them, a key investigative tool is completely unavailable to us, greatly hampering us in our ability to protect the patients and carry out our statutory mandate. Repeatedly we have sought to obtain them in situations of reported abuse. A month ago I asked to have access to incident reports in certain cases of alleged abuse of adolescents, but was refused. Again within the past week, hospital administration denied us the right to see incident reports we requested for certain patients. The problem of a lack of patient protection from abuse remains, creating a situation of danger for our clients.

EXCESSIVE RESTRICTION ON LIBERTIES OF PATIENTS

In the past year or more I have rarely seen children play outside of the hospital wards or be exposed to the fresh air. My clients have continually complained about the lack of exercise, the inability to use their energies, to run, to use the gymnasium, and especially to be outdoors. The prisonlike conditions in the adolescent unit seem to have worsened in the past year. Even though a majority of these children are simply awaiting placement in the community, in schools for special education or other open settings, they are locked in 24 hours a day, with rare exceptions, unless they are in school.

Adolescents have also repeatedly stated that while they are locked on the unit, there is a great degree of control by staff on the few activities they are allowed. Adolescents have to rely on staff to unlock a door each time they want to use the bathroom or a water fountain, so that if it was not convenient for staff, they might have to undergo significant discomfort. Verbal abuse is allegedly commonly used by staff.

In some cases, children reported that they were not allowed to read, play games or watch television when first admitted to the ward, during the hours that the other children were permitted to go to school. This situation continued for several weeks in some cases, with the adolescents only being allowed to sit in chairs and talk but not play or have access to magazines, books or newspapers.

The adolescents are told that if they have good behavior, they will rise from level one to level four of the privilege system, and will be able to go outdoors more and have more freedoms, as a result of having achieved that level. However, even the few clients I have who have been able to achieve level four, have not been allowed outdoors to play. They were told, upon reaching that level, many weeks after their arrival, that it was now up to the team to award them the privilege. This never occurred in any case that I know of. At most, level three and four patients were simply allowed access to the occasional off-grounds activities such as skating or a movie, while other children were not.

Because the children were so often locked up without fresh air or activity, they told us, they would often get in trouble for small infractions or for aggressive play when they were trying to seek recreation and activity on the locked ward. There was also frustration and humiliation at the confinement which sometimes caused the children to misbehave. As a result, someone seemed to be restrained to a bed or put in seclusion and medicated by forcibile injection nearly every day, the adolescents reported. It is noteworthy that the Medicaid 1984 Periodic Medical Review of the adolescent unit (page 3-4), made a "Special comment on use of mechanical restraints (and) seclusion" in the adolescent unit. The team stated that review of the records showed that restraints were used too frequently without other alternatives of modifying behavior being observed. They also stated that efforts did not appear to be made to differentiate between normal behavior and extreme or abnormal behavior when using restraints and seclusion to control patients. They concluded that "It is strongly (italics theirs) recommended by the PMR team that mechanical restraints be used in a more judicious manner."

The lack of freedom and of access to fresh air and exercise is a similar problem in the adult unit of the hospital. With the absence of meaningful activities and treatment, the privilege to use the attractive, parklike grounds of the hospital, was a main form of therapy used in the past. Patients who achieved a certain level of good behavior, would be allowed passes to go outside, use the hospital canteen to buy personal items they needed or have coffee and socialize with others. Many patients had grounds passes for years. The statutory Patient's Bill of Rights, N.J.S.A. 30:4-24.2 requires that patients be allowed all civil liberties, and have the right to access to outdoors, to regular exercise, to access to buy needed items for personal use and to be in the least restrictive environment possible.

Therefore, staff at the hospital and patients alike were very alarmed when in December 1983, the grounds pass of every patient in the hospital was suddenly revoked. All the wards which had open doors were locked. They have never been reopened. Patients were not allowed outside for any reason and therapeutic programs that occurred off the wards were permanently ended. Patients who had had passes for ten years were suddenly locked up.

The reason for this action was apparently the escape of one patient, who had committed a crime in the past, causing the incident to reach the local newspaper. Although the patient was returned the next day to the hospital without incident, the patient's grounds passes were not reissued, and open ward programs remained closed. This situation continued throughout the spring and summer, for a period of eight months. The patients missed experiencing two seasons of that year. When the weather became hot, the swimming pool, which had been open every year in the past for patient use, was not open to the patients. At that time only ten patients in the hospital were ever allowed outside the wards. For eight months noone else had gotten any fresh air or exercise. I was unable to advocate for patients to even go to vocational rehabilitation or other programs, because staff was afraid that if they referred them they would be disciplined since patients had to go outside to receive these therapies. Even clients waiting for placement in the community and already ordered discharged by the court were locked in. One of my clients, who had difficulty finding housing in his community, had to wait for one year on a locked ward, unable to do anything but sit in a chair and watch television or lie on the floor up until the day he was discharged. The situation was the same for hundreds of other residents. Patients were even rebuked for going near the window to try to get some fresh air.

Even our clients in the Vroom building, which is a prison hospital, were getting more liberties at that time, since they are allowed to go outside and participate in sports during each day, or to use the pool in hot weather. Staff in the civil unit were extremely upset, they told us, because patients' mental conditions were worsening.

Finally, unsuccessful in negotiations, our office had to bring suit to alleviate the problem. Although significant improvements were made, the hospital grounds are still relatively empty at this time. In Marlboro hospital the situation of lockup continues to be as severe as it had been at Trenton Psychiatric Hospital before we brought suit. There, because there is even a greater population at patients, it has caused a tremendous overcrowding in ward conditions, and the many open programs there are now entirely locked.

ABSENCE OF PROGRAMMING FOR PATIENTS, RESULTING IN WAREHOUSING OF CLIENTS AND DEPRIVATION OF RIGHT TO HAVE MEANINGFUL ACTIVITY AND NEEDED TREATMENT

When the official body for accreditation of psychiatric hospitals inspected Trenton Psychiatric Hospital , to decide if the hospital met requirements for federal funding, I saw for the first time activities being conducted out on the wards involving all the patients in creative arts, crafts and other rehabilitative therapies. One day during one inspection I came to a ward of young male patients and saw them busily occupied at a table, assembling very handsome plywood models of airplanes, cars and other vehicles. I was amazed at how attractive the materials were, and how the patients seemed to be enjoying their activity. It was the first and last time I ever saw that particular activity performed on the ward. Other people in our office observed during this inspection that staff were taking patients out to play ball with them, using equipment never seen before or since. Also at this time we saw patients were taken on buses outside to go for rides or picnics. But unfortunately when the accrediting agency left, the therapies and activities disappear too.

Most of the day, the majority of patients still lie or sit on the ward, in chairs or on the floor. Many of them want to have certain activities, to have vocational rehabilitation, to improve their daily living and working skills but noone will refer them to these programs. There are a very few programs in the hospital that take a small number of patients each, and lucky patients may get a few hours of activity in a week. But many, many patients are still consigned to sitting in front of the television set or sleeping on the floor for many days and weeks on end. When the accrediting agency comes, the hospital shows it has the ability to treat patients for a period of a few weeks, and then the effort stops. Staff members at Trenton Psychiatric Hospital have complained to me how during the year in preparation for accreditation, so much writing of patient treatment plans and records was demanded by administration that staff have no time to spend with the patients. This was also reported in _The Trenton Times_ in their article of July 2nd, 1984. In the article one staff member is quoted as saying, "There's a lot of treatment planning but very little treatment" and another therapist explained, " Somehow, we've been bound up in a paperwork horror show' so that "90 percent" of a therapist's time is spent in documentation.

Since I have been working with hospital patients, the treatment plan for each patient has increased from three pages to nine pages, with little change in the situation of the patient's lives and the lack of treatment. Recently as a matter of fact the hospital administration ordered the layoff of several recreational therapists, including two of the three art therapists available to the whole hospital and one of the two horicultural therapists they had, cutting many patients off in the middle of therapy with no substitute.

Because some of the patients are dependent upon training to have a realistic opportunity to leave the hospital and live in the community, the lack of treatment is one of the most crucial issues for them. Without it many live without hope of ever living in the community again or leaving the hospital walls.

The statutory Patients' Bill of Rights in New Jersey which mandates patients' rights to adequate treatment, to civil liberties, to fresh air and to other human rights is still very far from realization. Instead the reality for many patients in these hospitals is only the four walls of the ward they live on, without knowledge of when, if ever, they will be able to be free.

(EDITOR'S NOTE: Due to printing limitations and in the interest of economy, certain documents supplied for the record by Ms. Sands were retained in the files of the Committee where they may be researched upon request.)

INTRODUCTION

DEPARTMENT OF THE PUBLIC ADVOCATE:

ENABLING LEGISLATION

(NOTE: The above material was retained in the files of the Committee.)

HISTORY OF EFFORTS OF THE PUBLIC ADVOCATE TO SEEK INVESTIGATION OF ABUSE IN TRENTON PSYCHIATRIC HOSPITAL

A. Internal Memo--Abuse at Trenton Psychiatric Hospital

B. Memo re Proposed Investigation

C. Memo re Meeting with Commissioner and Attorney General for the hospital administration.

D. Memo from Attorney General Advising Against Investigation.

E. Memo Public Advocate Regarding Inability to Prevent Abuse.

F., G. Letters to Human Service Administration Proposing Meetings.

H. Letter regarding meeting.

I. Memo regarding Further Reports of Abuse at Trenton Psychiatric Hospital.

(NOTE: The material listed above was retained in the files of the Committee.)

I. INADEQUACY OF INVESTIGATION BY POLICE AND HOSPITAL ADMINISTRATION

1. Memorandum from Laura Roth
   Re: S.L. Abuse Investigation

State of New Jersey
DEPARTMENT OF THE PUBLIC ADVOCATE
DIVISION OF MENTAL HEALTH ADVOCACY
CN 850
TRENTON, NEW JERSEY 08625

JOSEPH H. RODRIGUEZ
PUBLIC ADVOCATE

LAURA M. LE WINN
ACTING DIRECTOR
TEL. 609-292-1780

MEMORANDUM

TO: Carol Sands, Esq.
FROM: Laura Roth LR/sal
DATE: March 5, 1985
RE: S.L. - Abuse Investigation

As we discussed, I am drafting an account of the above investigation that Michael Buncher and I handled in August, 1984. This case not only involved physical abuse by an attendant against a patient, but also uncovered attempts by the hospital administration and institutional police force to dismiss the attendant's wrongdoing. Details follow.

LR/sal
Att.

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3/5/85

S.L. - Abuse Investigation

1. S.L. was a patient in Greystone Park Psychiatric Hospital (GPPH), a large state institution located in central New Jersey. In late August, 1984, he called our office complaining he had been assaulted by a ward attendant and also that he was not being permitted to press charges against the employee.

2. The following day, a co-worker (Michael Buncher) and I visited S.L. at GPPH where we interviewed S.L., reviewed his hospital record, and spoke with employees and institutional police about his allegations.

3. We noted that the client's lip was bruised and we felt a lump on his head. S.L. stated he argued with a ward attendant and the worker spit at him as well as hit him.

4. We reviewed the Incident Report filed in S.L.'s chart. The report format itself is noteworthy in two respects and demonstrates the hospital's inappropriate attitude toward allegations of abuse made by patients. First, the report, as a formal instrument which staff must complete whenever unusual incidents occur, is designed in a way to discourage reporting of employee abuse. Under the category of Assault, staff are to check-off the type of assault which took place. While there are several sub-categories to choose from such as Patient-to-Patient Assault or Patient-to-Staff, there is no sub-category specifically for Staff-to-Patient Assault.

   A second bias contained in the formal Incident Report form is the failure to allow space for patients' statements, while permitting comment by staff. This shortcoming not only prevents patients' comments from being formally logged in the hospital record, it also demonstrates the administration's attitude that patients' perceptions concerning abuse are worthless.

5. Despite the inherent drawbacks in incident reporting, this particular case was startling because while the attendant himself made two written admissions (one in the Incident Report and another elsewhere in the chart) stating he had indeed hit S.L., three staff members who saw the incident said they did not see the attendant hit S.L.

6. Nursing supervisors are responsible for conducting investigations into such incidents. In S.L.'s case, the supervisor counseled the employee, but cleared him of wrongdoing. The supervisor's notes reflect acceptance of the worker's statement that he believed he was in self-defense when he struck S.L.

7. As institutional policy dictates, Greystone police also conducted an investigation. Here again, after interviewing several persons including the patient, institutional forces uncovered no wrongdoing on the part of the worker. Furthermore, according to S.L., the institutional police refused his request for assistance in pressing charges against the employee. I was present when Michael Buncher phoned the grounds' police and substantiated this aspect of S.L.'s allegations. Thus, despite the employee's admissions and the client's desire to pursue a criminal action against him, S.L. was flatly denied any opportunity to press charges and no disciplinary measures were taken against the employee.

8. During the course of this investigation, we uncovered other questionable police practices. S.L. Claimed that grounds' police interviewed him about the incident in the presence of employees and within ear-shot of the alleged perpetrator. This last allegation was not new to me. It had been an issue I battled over at least five years ago and believed had been resolved.

9. Upon completion of our investigation, we contacted the Department of Human Services' Police Chief. We phoned him and conveyed our findings -- admissions by the employee, his police staff's refusal to transport S.L. to municipal court, and unethical as well as substandard police investigative procedures. Although the Chief requested copies of the employee's statements, he acted expeditiously upon receipt of the records we sent him.

10. Ultimately, the Chief validated our every finding. First, he quickly issued a directive (see memorandum dated August 28, 1984) ordering all institutional police to afford privacy to interviewees at all stages of the investigative process. (See Exhibit 1, a memorandum from the Chief dated August 28, 1984.) Secondly, the grounds' police assisted the client, and S.L. pressed formal charges against the employee. Finally, upon the Chief's re-examination of the employee's written statements in S.L.'s record, the employee was fired. (See Exhibit 2, memorandum dated September 7, 1984.)

11. Thus, despite the ward attendant's written admissions and S.L.'s repeated requests to press charges, institutional forces acted completely indifferent and self-serving. The in-house systems (nursing staff and police) for investigating patient abuse utterly failed the client. Justice would not have occurred had we not had the authority (and clout) to advocate for S.L., and the ability to circumvent as much of the institutional forces as necessary in order for S.L. to receive an objective hearing of his grievances.

DEPARTMENT OF HUMAN SERVICES

INTER-OFFICE COMMUNICATION

To: All Personnel
Human Services Police

Date: August 28, 1984

From: Angelo (Sonny) Ferrara
Chief of Police

Subject: Guidelines for Questioning Suspects & Witnesses
(Special Order #24)

This office has received a complaint from the Public Advocates office that a client was questioned about a complaint in the presence of the employee who allegedly assaulted him/her, and that this type practice is prevalent in the department.

Complaintants or victims shall be questioned or interviewed in a location which is suitable to the privacy required. Under no circumstances should staff or other employees be present when a client is questioned especially if they are suspects in the complaint.

If a clinical person is required to be present they shall not have been involved in the action causing the complaint.

When required, witness to formal statements taken shall be police personnel.

In questioning employees in a police investigation, Union representatives shall not be allowed to be present at the questioning or interrogation. The same privacy to conversation will prevail with any person being interviewed or questioned.

c Capt Kosco
Capt Fish
file

DEPARTMENT OF HUMAN SERVICES

INTER-OFFICE COMMUNICATION

To: Michael Buncher
Assistant Deputy Public Advocate

Date: September 7, 1984

From: Angelo (Sonny) Ferrara
Chief of Police

Subject: Greystone Investigations - L

Received and reviewed your letter of August 28, 1984 and I was also deeply concerned if your allegations were valid.

An investigation was conducted and it revealed your allegations were valid. This in turn led me to correct this situation throughout the state in all our facilities by issuing "Special Order #24, a copy of which is enclosed.

In reference to the allegations of Mr L , an investigation was conducted and it was determined that he had in fact been assaulted. The employee who assaulted Mr L was arrested and a complaint signed against him by the Human Services Police for Assault. Further, the employee has been terminated from Greystone.

c Mr Wilson, Acting Deputy Commissioner
Mr Dailey, Assistant Commissioner
Mr Smith, Assistant Commissioner
Mr Rodriguez, Commissioner
Ms LeWinn, Acting Director
file

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[illegible]
PUBLIC ADVOCATE
MENTAL HEALTH TRENTON

RECEIVED
SEP 11 1984
PUBLIC ADVOCATE
MENTAL HEALTH TRENTON

II. EXAMPLES OF UNWILLINGNESS BY HOSPITAL ADMINISTRATION AND HUMAN SERVICES POLICE TO INVESTIGATE ABUSE

2. Affidavit by Thomas Liguori
3. Affidavit by Maureen Kelly

STATE OF NEW JERSEY: :
ss.
COUNTY OF ESSEX: :

:

AFFIDAVIT

I, THOMAS D. LIGUORI, of full age, being duly sworn according to law, upon my oath depose and say:

1. I am a field representative employed for the past ten years by the New Jersey Department of the Public Advocate, Mental Health Division. I have been a member of the field office in Essex County for nine years. In this capacity, I represented patients at Essex County Hospital Center, Marlboro Psychiatric Hospital (the latter a State psychiatric institution) and other hospitals. I have recently become a member of the class action field office, where I continue to represent patients at Marlboro Hospital in regard to civil rights. I am also involved in the investigation of community services that are available to patients in other counties.

2. On December 20, 1984, I was contacted in the late afternoon by H . L , the stepfather of a client at Marlboro, D G . Mr. L told me his daughter had been raped by several convicted prisoners from Rahway Prison who had been working at Marlboro Hospital in its' cafeteria.

3. The next morning, December 21, 1984, I went to Marlboro Hospital and spoke with D .. She told me that on December 10, she had been raped by several prison inmates working in Marlboro's cafeteria. They told her that if she told anyone about it, they

would kill her. She seemed quite terrified about this, and told me that they were going to kill her because she reported the incident. I tried to reassure her that she would be all right.

4. According to D ., she reported the incident the day it occurred, which was December 10. It had occurred early in the morning, and, in the later afternoon, she had tried to tell a doctor about it. She had been upset and had scratched her wrist slightly. The doctor did not listen to what she was saying, but observing the scratch on her wrist, immediately transferred her automatically to the Intensive Treatment Unit, a higher security unit. A nurse there did listen to her story and notified the institutional police.

5. I examined D .'s medical chart that day, the 21st. Between the day of the incident and that day, eleven days later, no gynecological exam had ever been done, nor any lab test to determine the fact or absence of evidence of rape, or the presence of medical injury that might need treatment. D had only been examined to see if there were any bruises on her body, but not examined gynecologically.

6. The police report, which I was able to see on January 28, 1985, stated that the police detective had requested that the hospital provide a gynecological exam on the day after her incident, the 10th of December. The report stated that Dr. Q of Marlboro refused to do a gynecological exam because he stated Ms. G had menses. The report did not say how Dr. Q knew if it was menses or bleeding due to some other trauma. He apparently said that gynecology was not his field and he could not do an exam. The hospital did not follow up to find an appropriate physician to do

BEST COPY AVAILABLE

an exam.

7. Ms. G 's medical records showed no psychiatric counselling for rape was provided to her following the incident. I spoke with the staff on duty that day about the incident. They laughed when I mentioned it. They were all aware of it because it had been in the newspapers.

8. At Ms. G 's request, I asked her treating physician, and the Medical Director, Dr. Binkowsky, and the nothern regional community services supervisor, if she could be transferred to Meadowview Hospital where she could be near her mother. Weeks passed, and despite my urging, nothing was done. Finally, when an attorney sought by the family threatened to file suit, Ms. G was immediately transferred within twenty-four hours.

9. At my urging, the Human Services police and the Internal Corrections Office at Rahway have pursued the matter. With much encouragement from me, an investigation was finally pursued, although much after the fact of the incident itself. Apparently, enough evidence was subsequently collected, despite the absence of evidence of the physical fact of rape, to bring the matter to the Grand Jury. I await the report of Internal Corrections regarding the evidence collected. The dectective from Human Services had contacted the Assistant Prosecutor of Monmouth County some time after the incident, and was advised that due to the time lapse after the rape, seeking an examination would be unlikely to yield the evidence needed. It is unclear if sufficient evidence can be obtained without that examination, to establish the fact of rape. The rape was treated as a fact only after it was corroborated by the head officer at

Marlboro Camp, where the prisoners were incarcerated at the time of the event.

I hereby attest that the foregoing statements are true.

THOMAS D. LIGUORI

Sworn and subscribed before me this

19th day of March

1985.

Patricia Bini

PATRICIA BINI
A NOTARY PUBLIC OF NEW JERSEY
My Commission Expires Feb. 5, 1986

AFFIDAVIT

I, Maureen Kelly, being of full age do hereby depose and say

1. I am a Registered Nurse, licensed by the state of New Jersey. I am employed by Donnelly Memorial Hospital, a nursing home where I care for geriatric patients in need of total nursing care. I have one son, James Kelly, who is a patient at Trenton Psychiatric Hospital since June, 1984. James is at the hospital due to brain damage he suffered in mid-June, 1983 caused by Herpes virus type 1 encephalitis. At that time he was age 25.

2. Prior to his illness, James was employed as a housepainter. His age is now 27. His illness is characterized by a severe loss of memory and difficulty with retention of new memories. Prior to his hospitalization at Trenton Psychiatric Hospital, he was in residence at a series of medical hospitals. He is inappropriately placed at Trenton Psychiatric Hospital and has been discharged by the Superior Court Law Division from Trenton Psychiatric Hospital pending placement in a suitable facility for rehabilitation of his loss of memory and other functions. I am his legal guardian and am assisting in finding a placement for him.

3. James has been staying on Ward East 1 of the Drake building at Trenton Psychiatric Hospital. On October 4th, a Thursday, I picked James up from the hospital after work at approximately between 3:30 and 3:45 P.M. I took him home with me to stay overnight and to go for a neurological evaluation the next day in Piscataway. The purpose of the evaluation was to help Jim find placement in an appropriate treatment center for rehabilitation of his loss of brain function.

4 During his visit with me at home, James kept mentioning during his conversation that he had been encountered by a man who took a knife to him. He said that the man said to him "Do you want to die?" or "Do you want to be good?" James said that he said yes, but that he was afraid. I did not pay much attention to this, because due to James' brain damage, sometimes he makes sense and sometimes he doesn't.

5. When I returned back to the hospital with James the next day, at approximately 7:45 P.M., a patient named Lorraine Peer came to the door when we arrived and said to James as we came in, "Did you tell her about the blood on your pajamas?" I asked Ms. Peer what she was referring to. She said she had seen blood on the back of James' pajamas earlier that week on Tuesday, Wednesday and Thursday. Another patient, Nathaniel Mc Rae came over to us and said that he had seen blood on the back of James' pajamas on Thursday. He said he had also seen blood in James' bed when an attendant changed the sheets that day. Another patient, Beverly Cooper then came over. She said she did not want to get involved but admitted that she had seen blood on the rear of James' pajamas too. I asked them all if the they were sure it was blood, and all three patients stated that the pajamas were red and that they were sure it was blood. They said the blood was on the rear of his pajamas.

6. As I am a nurse, I have permission for access to Jim's chart. I examined it and there were no progress notes at all in his chart for those days when blood had been seen on his pajamas by the other patients. No nurse was then on duty. I spoke to Ms. Fariole, an HST (which stands for human services technician, a kind of attendant). I asked her if she had any knowledge of an incident of abuse involving James. She said that such thing could not happen and than they had never had such an in incident. I

NURSE - NONE ON DUTY - REQUESTED SUPR. AND M.D.

asked for a ~~doctor and a nurse~~ to examine James She said I would have to wait until they could get to it and that they would contact me the next Tuesday (four days hence). I insisted that he must have an examination because he had been observed to be bleeding by three people. F~~inally, Ms Fariole called Ms. Gray, the nurse supervisor. She then told me that Ms Gray was too busy and couldn't come.~~

7. I asked Ms. Fariole to open the door so that I could leave with Jim to take him to Mercer Hospital to be examined. I had a brief visit ordered by the doctor for Jim until 9:00 P.M. It was still only 8:00P.M. and I had one hour left. I told her my son was not committed but was discharged by the court pending placement and that I was his legal guardian, so there was no basis to keep him confined and out of my custody. She refused to let me take him out.

8. I called the Ewing police and was told I had to call the grounds police at the hospital. However, Ms. Fariole said I was not allowed to call the grounds police. She said she was not allowed to call them either. ~~She refused to call a doctor or an administrator~~. Finally, she again called Ms. Gray.

9. I asked the attendants on duty for their names. I got Ms. Fariole's name although she was reluctant. Another attendant, Ms. Sumter willingly gave me her name. However a third attendant named Nathaniel, who was standing by, refused to give me his name. He had a name tag and I bent over to read it, and touched the card. He pulled away, and the card came into my hand. I had time to read the name, but he

grabbed it and got very angry at me He said he would press charges against me

10. 45 minutes after the first call, Ms. Gray arrived She did not talk to me but went to look at the chart and use the telephone. The grounds police then came.

11. Thompson and Pastore were the names of the patrolmen. First they went into a cubicle with Ms. Gray after they arrived. Then they came out. I explained the situation to them, and my fears that Jim had been molested. One patrolman did the talking. He denied that it was true. He refused to let me take my son to Mercer Hospital. At first Patrolman Thompson said I could only visit with Jim on the ward. Then he insisted at 9 P.M. I leave without Jim. I told him I was Jim's legal guardian and that he was discharged pending placement and not committed. I was very frightened and upset because I did not want to leave the hospital without Jim. I ~~again~~ asked to see an administrator. Shortly, patrolman said that I can stay and MD. and administrator were on their way to see me.

12. A doctor arrived and I explained the situation to her. She denied that any abuse could have occurred. She told me I was emotional and the suspicion was unfounded. I said I want to go to Mercer hospital to have a physical examination ~~with emphasis on a rectal inspection for my son and that I wanted to be present at the examination.~~ The doctor said this could not be done. Ms. Patricia Biggs-Swain, the section chief of the Drake building arrived. I explained the situation for the fifth time.

13. MD. wanted to know what she could do for me now.

~~13. Finally after a great deal of insistence, the doctor agreed~~ to ~~do an examination herself~~. She did a rectal check in my presence but did not check for injuries anywhere else on his body. She examined only the rectum Since there was some feces present in the rectum the doctor said he was impacted and blamed the presence of blood on that cause

14. I saw the doctor write an order for treatment of the problem "stat" or on an emergency basis but according to the chart, the treatment was not given to him. The next day I had to ask again to have treatment administered. I had to seek out another administrator. It had to be ordered again. However, it was never checked for effectiveness. I finally had to treat my son myself for his impaction.

15. The test for blood in the stool which the doctor ordered at my request was not done (and still has not been done), so that no medical test to see if he was bleeding for medical reasons was ever given.

16. On the Monday three days after the incident, I was called up to the second floor to the office of Ms. Swain, the section chief. Ms. Swain and Ms. McCrea, a nursing supervisor were there. They talked in a very threatening and intimidating manner. They said I had been out of order and distraught the Friday before and that I had upset the HSTs. They asked me how Nathaniel, the HST whose badge I had touched, could care for Jim properly after this incident. They indicated he might not do as good a job or treat him properly. The sense of their statements seemed to be that he wouldn't care for Jim. Ms. Swain even said that due to this perhaps Jim should be transferred to another ward, the Medical Surgical unit (where people with medical illnesses are treated). They suggested Nathaniel could press charges against me for touching his badge.

17. During the conversation, Ms. Swain told me that I could have taken Jim off the ward for an examination at the hospital and had

permission to leave with him if I had only stated that I was his legal guardian and that he was discharged pending placement from the hospital. She said that these were the "magic words" to get Jim to have a visit off the hospital ward with me. I told her that I had used those "magic words" with the HST, the patrolmen, and the doctor all to no avail, and was unable to get permission to leave the ward with Jim.

18. Shortly after this conversation, a note appeared in the doctor's order sheet in James' chart saying that I could not take James out any longer with just a doctor's order but that it required both a doctor and an administrator's order to take him out of the ward. It has been extremely difficult since then to obtain permission for visits with my son to our home.

I hereby attest that the foregoing statements are true.

Maureen C. Kelly

Maureen Kelly

Sworn and subscribed
before me this 21st. day
of February, 1985.

Carol J. Sands
attorney at law
State of New Jersey

III. UNWILLINGNESS BY OTHER AGENCIES, SUCH AS THE DIVISION OF YOUTH AND FAMILY SERVICES TO INVESTIGATE ABUSE OF ADOLESCENTS

4. Affidavit of E.F.
5. Affidavit of
6.a and 6.b Affidavits of

(these names are CONFIDENTIAL)

AFFIDAVIT

1. I, E F , am a resident at the Bridgeton juvenile detention center since September 29th, 1984. Prior to this date, I was a patient at Trenton Psychiatric adolescent unit, for a period of about one week, from Friday, September 21st to the above date.

2. During the entire time I was at Trenton Psychiatric Hospital, I was locked inside without fresh air, and only got out for a fire drills. The first day I arrived, Mr. Wilson, the program coordinator, who had not yet met me, came up to me and said, "If you act up, you're gonna be treated like a fool. We'll show you how it's done." During my stay the staff on the unit continually threatened to call Mr. Wilson, if they did not like something we were doing.

3. The day after I arrived, on September 22nd, a patient called my family unkind names, and because I replied I was rebuked by a staff member, Mr. Brunnage. We called each other names, and Mr. Brunnage called Mr. Wilson. Mr. Wilson took me into the seclusion room. He put his things down and took off his vest. He called me a "creep." I said, "Don't call me names; I didn't call you a name." He said, "I'm going to give you a free trip to the dentist. I'm going to knock your teeth out." He threatened that he could beat me up and not have a mark show, and said he would knock the hell out of me if I did not fight him. I sat down in the seclusion room and did not reply. He is about a foot taller than I am and weighs a great deal more than I do. He did not beat me up that time, but he did smack my face and said, "You look at me when I talk to you. I'm not your Mom or Dad." He pushed me and grabbed my face and squeezed it. He kept saying, "Look at me when I talk to you."

4. Mr. Wilson threatened me and other patients on several occasions. I have witnessed him pull people and grab them and throw them down on chairs. He calls patients "creeps" and "assholes". Other staff also are physically abusive. Ms. Adams, a nurse hit me on the back, leaving a red mark because she was angry at me. Other staff members hit and curse patients if they do not get out of bed immediately in the morning.

5. Every morning the staff would throw cold water on a patient named Dave because he did not get out of bed fast enough. Since he is slow they seem to take advantage of him. The staff are very verbally abusive also, and hurry the patients continually to shower, get up, or dress, but if you reply they threaten to call Mr. Wilson. Mr. Wilson also threatened another resident, Steve, in my presence, because he would not go to school. He told Steve that if he smoked a cigarette, he would call the fire chief and file an arson complaint. On another occasion I asked a nurse to read the newspaper and she said, "I'll throw it in the trash before I give it to you," and threw it away, so that I could not have it.

6. During the day, if you needed to go to the bathroom or get a drink of water, the staff had to open a locked door. Sometimes you would have to wait quite a long time to use the bathroom at all. When you showered, the door had to be kept open, we were told, though it was right in front of the nurses's station. They would continually come in to hurry you up in the shower.

7. There are many large roaches in my unit, and I killed one that was two inches long, which I found in my room. I had to sleep in the middle of the unit, but was not told why. The only activity during the day was watching T.V., but that was not permitted from 9A.M. to noon and 1 P.M. to 3P.M. while the other residents were in school, so that during most of the time, there was no activity permitted at all. Staff rarely allowed us to have cigarettes, so that although we had little to do but spend much of the time waiting to have one, we often did not get any.

E F

October 10, 1984

Laura Roth
witness

Brenda Spaltore
witness

October 10, 1984

AFFIDAVIT

1. I, S R, am a patient at Trenton Psychiatric adolescent unit admitted here because of drug abuse. I reside in Kennedy Cottage, the admissions unit of the adolescent section.

2. Two weeks ago, I ripped up the Smurf doll of another patient. Mr. Wilson, the program coordinator, came in and took me into the seclusion room. He took off his jacket, his rings and his watch and said, "Now I'm ready for you punk, you're in the big time now and if you start anymore ruckussing in my home I'll kick your ass." He asked me if I wanted to fight him and I said, "No, that's not what I came here for." Then he put his clothes back on and left the room.

3. Recently Mr. Wilson also banned me from smoking for the rest of my stay in the hospital because I did not want to go to school. I told him I was 16 years old and did not want to continue school. He threatened to drag me by my ears to school, and he seemed to intend to do that until my friend mentioned the Public Advocate, and then Mr. Wilson just wrote something in my chart. However, he told me that if I smoke one cigarette while I am here he will call the fire department and charge me with arson. This is a real problem for me because I have been smoking for six years.

4. I have not been outside either in the day time or at night for three full days as of today. The only activity is watching television, although this is not officially permitted during the daytime. Sometimes it is allowed by certain staff, unofficially; sometimes it is not. As further punishment for misbehavior over the weekend, I was deprived of my radio, my guitar and its amplifier.

5. The staff nurses and aides, like Ms. Watkins and Mrs. Hill are sometimes verbally abusive, and occasionally physically abusive. I witnessed Mrs. Adams slap a resident, Edward Ford, and Mr. Kirkland, another aide, recently kicked and shoved another resident, John, who seems to be mentally impaired. I was able to see Mr. Kirkland through an open door and window push John and kick him because of a verbal insult John gave Mr. Kirkland.

6. It is difficult to eat the poor quality food here, I have asked my parents to bring me food to keep here. The staff has control over distribution of our food from the refrigerator, which they have the only access to. I noticed that half of my cookies, and my donuts were eaten and half of a liter of coca-cola my parents had brought was missing after they had brought it.

S R

Sworn and subscribed before me
this 5th day of October, 1984.

Beth Barnes

AFFIDAVIT

1. I, , am a patient, 17 years of age, residing at Trenton Psychiatric Hospital, in the adolescent unit. Today I will be leaving the hospital for placement at the Today program in Newtown, Pennsylvania, a program for rehabilitation from drug addiction. I have been at this hospital since September 19th, 1984, approximately two weeks. I came here to recover from drug toxicity.

2. Over this weekend, a rule was issued banning the smoking rules on the unit, which allowed us one cigarette per hour. We were told that Mr. Wilson, the program coordinator of our cottage, Kennedy cottage, had ordered this. The staff still occasionally gave cigarettes out, but only to those patients they desired to give them to. This varied from shift to shift, so that on some shifts, no patients got cigarettes, and on others, only a few patients got them, depending on whom the staff felt like giving them to. There seemed to be no rhyme or reason as to the privilege, and the mystery of not knowing whether they would be able to smoke or not upset and agitated the patients very much.

6b

IV. DURING OUR INVESTIGATION, ADOLESCENT PATIENTS AND STAFF WERE FEARFUL OF RETALIATION BY OTHERS AND AFRAID OF SPEAKING TO THE HUMAN SERVICES POLICE

7. ABUSE REPORT

AFFIDAVIT

1. I, ., am a patient at Trenton Psychiatric Hospital, aged 17 years old. I have resided in Kennedy Cottage of the adolescent unit here since Wednesday, September 23, 1984,(approximately one week). I was brought here because I was under the influence of cocaine and undergoing withdrawal symptoms, which caused me to try to hurt myself. Because of this I was sent here by Newton Memorial Hospital of Sussex County. I am now free of drug influence.

2. Since I have been here, during a period of one week, I have been outside for only 45 minutes. I was told by Gail Rudolph, a counsellor, when I first arrived, that I must start as an admittee on the hospital's level system (which means I cannot go outside at all). I am treated as a new admittee even though I have been told that I am not in the appropriate placement here at the hospital, and should be in a program for drug counselling which is non-psychiatric. I am not even on any medication. However, I am told I must wait till I can be on Level 1 before I can go outside at all, which can occur only after a certain number of days. If I achieve level one, then theoretically I am allowed two fifteen minute breaks per day during which I can then go outside, if there is adequate staff available. I have not been told what my level is currently. I get no exercise or fresh air.

3. It is apparently not possible to go to school until you are here at least nine days, under the levels system. Since I am not allowed to go to school, I have to stay in the cottage all day. During the day, I and the other patients are not allowed to watch television, or do any other activity. There are no books or magazines on the ward, and a patient stole the only one I had. It is very boring with nothing to do. The only thing I can do is talk to the other patients, most of whom have severe psychiatric problems, rather than a drug problem like mine, and therefore they are hard to talk to. Other than this the only activity is following staff orders to clean and sweep, which must be done exactly to avoid getting into trouble. If it is not done exactly right, staff threaten to write a bad note in your chart or take

some other action against you.

4. The building I am in is full of cockroaches. A staff member killed one last night that was very large. I have asked to sleep on the unit near the nurses' desk because of the number of cockroaches in my room. There are also either rats or mice in the walls, which you can hear. The staff members say there are many of them here. The bathrooms and showers are extremely dirty and I am concerned about having to use them, because they do not seem to be cleaned. We are also allowed no privacy when showering, and the door is left open despite the fact that female staff are on the unit.

5. Since many of the patients are not well, they sometimes will bother me. Staff does nothing about this. When a resident hit me in the arm, I was blamed for it, and was told it should not concern me. Although I realize many of the residents are not well , it is hard to be on a unit with them for many hours each day and not respond to annoyances and threats or verbal attacks. It is difficult to stay out of trouble with the staff because I am not permitted to respond to a patient even if he should continually harrass me. Although I have a lot of control over my responses, it is very difficult to handle this hour after hour without a break. Even if I got a few minutes outside once in a while, I feel I could handle it better. Since the staff put people in seclusion even for verbal arguments, I have to be very careful what I say to stay out of trouble.

6. Ms. Clark, a nurse on the unit frequently curses the patients. A lot of such verbal abuse occurs. Yesterday morning she told me to get up out of bed. I have been sleeping on the unit, despite the lack of privacy, because I am concerned about the number of roaches in my room. When I hesitated about getting up, she came over and slapped me on the back of my legs and shouted to me to get up. I have also witnessed one other patient, Edward Ford, being hit since I am here. Ms. Adams, a staff member, hit him on the shoulder last evening to punish him for an action she disapproved of. Physical as well as verbal abuse seems to be permitted here.

7. When staff tell us to do something, and we refuse, or don't do it

exactly right then staff say they will write a bad report in our chart, which will cause us to remain longer in the hospital. Staff continuously insist that when they tell us to do something, such as sweep the floor, turn on the television, get out of bed, brush our teeth, change our clothes or shower, we must do it immediately or else they begin to threaten us. It is very difficult to stay out of trouble and to avoid getting punished. It is necessary to work very hard to gain any freedom from the locked ward, under the level system.

8. We are often threatened with revocation of our right to smoke one cigarette per hour that is allowed. Staff also threaten patients with restraints and with Thorazine or other medication if they do not obey. If a patient refuses anything, (for example, I refused bloodwork because I had already had it done at Newton Memorial Hospital), then the staff tells them they will retaliate. A staff member told me two days ago that we have no rights because we are adolescents and we are in his cottage.

9. It is necessary to ask staff to open a locked door each time you wish to go to the bathroom or even get a drink of water, (since the fountain is broken). Thus you are completely dependent on the staff's good graces and must please them or you will be very uncomfortable. Due to this situation, I am often very thirsty. There is a real atmosphere of fear in the cottage, and most of the patients are afraid to speak up for their rights. Even if staff object to your attitude, (for example, if you state that you don't think you belong in the hospital), they will harrass you, and you will be very likely to end up in seclusion.

10. Mr. Wilson is the program coordinator, and when we do something staff disapprove of, they say "I'll call Mr. Wilson." Mr. Wilson threatens many of the patients and carries a long whiplike object on his keychain, which he swings. The other day, he came in and said, "I don't love any of you faggots." I have heard him call patients "punks" and "creeps."

11. Staff sometimes do not allow patients to receive telephone calls, to use the phone, or to go to dinner. One resident was not ready for dinner

on time the other night because he was doing something else. The staff left the unit without taking him and refused to take a tray back so he could eat. The resident had to go without dinner. This has happened to two or three residents since I am here, and seems to happen frequently. Also yesterday, the staff refused to let a patient, Steve Rosten, buy snacks from the cart that comes to the unit. I was also not allowed to buy food form him.

11. Last night a resident hit me with a pack of cigarettes, throwing it at me and hitting me in the neck. I got angry, and I spit on the floor. I told the counsellor, Mr. Bundage what happened and he said I was a liar. Several other residents defended me and told him they had witnessed what happened. He apologized but then he refused to give me the evening snack of juice and peanuts. He said "We can put you in isolation and refuse you visiting rights". He knew my parents were visiting me that evening.

Sworn and subscribed before me this
29th day of September, 1984

Carol J. Sands

Carol J. Sands, Attorney of the State of
New Jersey

ABUSE REPORT

I. IDENTIFYING INFORMATION

A. Children's Names:

1. Steve Ralston
2. Michael Forte
3. E F
4. J G
5. F R
6. W C
7. J M
8. K G.
9. B C
10. E C
11. W M
12. D G

B. Institution:

Kennedy Cottage, Adolescent Services Unit,
Trenton Psychiatric Hospital

C. Investigating Office:

Division of Mental Health Advocacy, New Jersey Department of the Public Advocate with assistance from the Department of Human Services Police and a representative from the Adolescent Services Unit.

D. Date of Investigation:

The investigation commenced on September 25th upon receipt of our first phone call. Interviews of nine (9) other residents were completed on October 12, 1984. Additional contact with residents for follow-up purposes and clarification is being maintained by our Division.

II. ALLEGATIONS

A. Affidavits

During the last week of September, 1984, Carol Sands, Esq., was notified by one Kennedy Cottage resident that he and two other residents had complaints regarding staff. Three residents were interviewed and reported incidents of verbal abuse, threats and physical abuse by Kennedy Cottage staff; civil rights violations were also reported. Ms. Sands and Ms. Barnes, Field Representative, drafted three affidavits (attached) describing the various allegations. A summary of the three affiants' allegations follow:

1. Physical Abuse

   (a) Mr. K (Staff)

      (1) Hit M.F. on left side of head.

      (2) E.R. witnessed K pushing and kicking another resident.

   (b) Mrs. A (Staff)

      (1) S.R. witnessed A slapping another patient.

      (2) Hit E.F. on shoulder and left mark.

      (3) E.F. witnessed staff hit other patients for remaining in bed.

   (c) W (Program Coordinator)

      (1) In seclusion room, smacked E.F.'s face, pushed affiant, and squeezed his cheeks because E.F. wasn't looking at him when spoken to.

      (2) E.F. witnessed W pull kids and throw them down on chairs.

   (d) Staff (no names)

      E.F. witnessed staff throwing water on one patient every morning because he did not get out of bed quickly enough.

2. Verbal Threats

   Re: Physical Abuse

   (a) K

      Told M.F.: "I have a right to hit you."

   (b) L W :

      (1) Took S.R. into seclusion after an incident with another patient involving destruction of patient's toy; took off jacket, rings, watch: "... if you continue to cause commotion here, ... I'll kick your ass."

      (2) Asked S.R. if he wants to fight him.

      (3) Threatened to drag S.R. (who was 16 years old) by the ears and force him to attend school.

      (4) E.F. witnessed W used by staff to threaten misbehaving patients.

(5) Took E.F. into seclusion room, took off vest and tried to remove his watch. Called E.F. names and further told E.F. he's going to give him "a free trip to dentist" and knock his teeth out.

(6) Told E.F. he could beat him up and not leave a mark showing and that if E.F. wouldn't fight him right now, he'd knock the hell out of him.

General

(a) W_____:

(1) Told S.R.: If you smoke one cigarette, I'll call the Fire Department and charge you with arson. (Witness: E.F.)

(2) A patient witnessed W threaten to call Fire Chief with arson complaint if he smoked a cigarette. (S.R./Witness: E.F.)

3. Verbal Abuse from Staff

(a) B_____: "I like watching people suffer." (M.F.)

(b) W_____: called patients

(1) "creeps" (E.F.)
(2) "assholes" (E.F.)

(c) P_____:

Patient exchanged racial epithets with Brunnage who then called W to discipline patient. (E.F.)

(d) Staff are always hurrying us along and are generally verbally abusive; if you respond in kind, staff threaten to call Mr. W . (E.F.)

4. Civil Rights

(a) Arbitrary application of smoking rules (M.F.)

(1) from shift-to-shift

(2) from patient-to-patient

(b) Restriction on going outdoors (M.F.)(E.F.)(S.R.)

(1) on weekends

(2) all week (except for fire drills (E.F.)

(3) several days (S.R.)

(c) Feelings of imprisonment which produced heightened tension and conflict between patients and staff (M.F.)

(1) restraints

(2) stat. orders of injectable meds

(d) Lack of programming on cottage in general produced heightened conflict between patients and patients and staff and patients (M.F.)

Not permitted to watch TV during day though nothing else to do (S.R.)

(e) Denial of privileges as punishment

(1) not allowed to smoke cigarettes if didn't go to school (16 year old) (S.R.)

(2) as punishment for misbehavior, deprived of use of certain personal possessions such as radio and guitar (S.R.)

(f) Food quality is poor (S.R.)

Parents bring me food which is kept in a refrigerator which only staff have access to. Patient noticed that a significant portion of his food (cookies, donuts, and soda) were missing. (S.R.)

(g) During showers, door must remain open permitting staff in nursing station to see boys naked. (E.F.)

B. Interviews of Male Kennedy Cottage Residents

After revealing the allegations to TPH authorities, interviews of all male Kennedy Cottage residents were permitted. Present were this writer, Laura Roth from the Division of Mental Health Advocacy, Department of the Public Advocate, Officer Richard Dlugokenski from Department of Human Services Police, and, at the insistence of the Adolescent Services Units (ASU) Administrator, Daryll Jones, Staff Trainer from ASU, Department of Human Services.

It was agreed that I would conduct the interviews. Toward the end of each interview, however, I invited the officer and Mr. Jones to ask questions, though often they asked none at all. The accounts from patients are presented in the order they were interviewed.

1. J G had been hospitalized for five weeks at the time we interviewed him. In response to questions about staff abuse, he replied that staff "yelled sometimes" but that no significant problems existed.

2. F R has been a patient there for one week. He had no complaints.

3. W C has been in Kennedy Cottage for four days. He states that there are problems but he will not give names or details until he is discharged next week.

   This patient described cottage staff as generally having "bad attitudes" creating an atmosphere more like a juvenile detention center than a hospital. When he was specifically asked about his contacts with Mr. L W , B said he did not like him and that he had witnessed Mr. W hit other boys, pull their hair and throw them.

   On October 18, this patient was discharged to his home and I called him there. He returned my call but stated he had decided not to get involved. He felt somewhat afraid, since it is possible that he may have to return there before his 18th birthday in January. He was willing only to talk in generalities and gave the following information:

   - He was not a witness to L W s choking of B C ;
   - Mr. W , particularly, is abusive when dealing with the residents. Specifically, he has seen Mr. W pick up and throw boys across the room.
   - Staff, in general, use excessive force when restraining residents: 'They don't just restrain people when they approach them, staff hurts them first.' He has seen staff pull patients' hair and smack residents heads against the floor.
   - When residents get into fights, frequently staff allow the fight to continue. Staff tell the residents that they have to learn to get along on the street. He has see resident W M repeatedly tell other patients to leave him along and staff refuse to intervene to possibly prevent a fight.
   - Staff laugh at residents in restraints.
   - Staff are verbally abusive and totally unhelpful to the residents. They often play cards or watch TV and will not respond to residents' questions or requests for assistance.
   - He has witnessed staff pull G (J M) around the room by his hair. J does not speak English and he does not provoke anyone. Staff call him names like "dirty little spic" and take advantage of him because he doesn't speak English.

- He saw B C restrained yesterday after Billy became enraged at an attendant who said something about Billy's parents (both deceased). Billy did not attack the attendant. Staff restrained him and kept him in restraints for 8 hours in spite of the fact that Billy was calm after an hour.
- He suggested that I interview J . G about staff abuse because he is often a target.
  (Home phone no: 609/)
  parent: A S

4. J M speaks Spanish and must be re-interviewed. However, he understood enough of the questions to ask us how the information would be used.

   He stated that he has been hit by staff. (See page 9.)
   (Home phone no: 201/)
   Brother: S M

5. K . G . has been hospitalized for one week.

   He stated that he was being restrained on one occassion for throwing a chair. The staff member choked him while putting him in restraints.

   (My notes on this client's interview need clarification.)

6. B . C has been in Kennedy Cottage for 16 months. He explained that staff can't threaten him because he's unafraid. Also, he says he feels no pain in his face or arms, so fighting hardly bothers him either.

   B told us of a recent incident involving Mr. W . He said that W stopped him from pursuing another resident by choking him in an armlock and causing Billy to lose consciousness. He also told us that Wilson calls patients names like "punk" and another dirty name which he refused to repeat in my presence.

   I called B on October 18 to ask him for details concerning the incident with Mr. W. where Billy lost consciousness. He told me the following:

   Last Tuesday, he was pursuing another male resident named J G in a back hallway, near the nursing office. Mr. W approached him from behind with an arm lock around his neck causing him to lose consciousness. When he regained consciousness, staff

(Mrs. C. , another female employee, Mr. W. , and someone named D) tried to put him in the seclusion room and then changed their minds and restrained him. B. thinks that Mrs. C and a former resident, B. C , may have witnessed Mr. W choking him.

7. E C has been hospitalized in ASU for two months. His only complaint was staff's "nasty attitude." No details or incidents could be elicited.

8. W. M has been hospitalized for four months. Upon initial questioning, W told us the staff is "pretty nice." Initially, the only negative comments about staff were that sometimes staff will not stop fights between patients. This, he explained, happened to him on one occasion. Also, he has witnessed staff hit residents. When I asked him if staff were acting in self-defense, he answered affirmatively.

As the interview progressed, and I revealed the kinds of things other former patients had said about staff, W made a turn-around. He made the following statements about staff:

- Mr. w is "rough" when he breaks up fights.
- Mr. W calls patients names like faggots and punks.
- The cottage staff have "tacky attitudes" -- they are not helpful to residents, they are nasty in their communications, and their attitude is, in general, bad.
- J G is picked on a great deal by patients and staff.
- Staff often curse at residents.
- Staff is far too rough when they break up patient fights, even minor fights. He has seen staff "slap, kick, and punch" patients. Also, he has witnessed 3-4 staff persons holding a particular resident while another staff person was free to punch and kick patient. In one instance, he witnessed a staff person yank out a clump of hair from a patient being held by other staff.
- In general, when a patient is restrained "staff has a party." Restrained patients are laughed at and taunted. One one occasion, W witnessed a staff person throwing a pillow onto the face of a restrained resident so that the resident was in continual fear of suffocating. The staff person was laughing.

- R S , an attendant, has a particularly bad attitude. He does not perform his job and assist clients.

- Staff regularly order extra food trays and eat hospital food. If a resident asks for a second milk, staff refuse to give it.
  (Home phone no: 201/ -)

I called W at his home on October 18 in order to pursue discussion of our first interview.

He was home on an extended visit.

He remembered our interview and his statement that he would give us more information about Cottage conditions when he is released. Technically, he had not been released. Nevertheless, W informed me that he does not want to be responsible for having any employees fired and did not want to go on record with his statements. I therefore, agreed to a confidential discussion and he told me the following Account:

- He witnessed staff holding B C while another staff person (Miss D) pulled hair out of his head. At the time of this incident, staff were preparing to put B in restraints and B was "a little" out of control but not terribly so -- certainly not to the extent requiring staff to use any means possible to stop him.

- Regarding the incident involving staff repeatedly tossing a pillow onto a restrained resident's face, W could not be certain of which staff or who the patient was since he observed this as he walked by a patient's room. The patient's room was next door to the "Mud Room" (the exit to courtyard) and it occurred early evening. He believes two staff members were involved and a Mr. S may have been one, but W is uncertain.

- W witnessed staff allowing other patients to beat up resident J G . This patient, says W , is childish and often a target of the other residents. Occassionally, staff have J stay in another area in the Cottage in order to prevent patient fighting.

- On a couple of occassions, W has "screamed for help" when other residents have threatened to attack him. On these occassions, Mr. H and Ms. C refused to intervene saying that W would "have to learn how to fight on the street himself."

W told me he has not complained to his parents about any of these things because he did not want to upset his mother.

J M - Re-interview

With the aid of a Spanish speaking interpreter, Carol Sands and I re-interviewed this client on October 19. He relayed the following information to us in confidence:

- On several occasions an evening shift staff member named "V " pulled his hair and/or dragged him by his hair to another room. This occurred as recently as yesterday evening when "V " dragged him by the hair to the shower room. On another evening several weeks ago, "V " dragged him by the hair in the T.V. room again, because staff wanted him to bathe. J believes many residents witnessed this and named B. C , E. C , D. G , and J. G . as people we might question. J describes V as a black man, bearded, without glasses, and on the tall side.

- When J was asked whether he witnessed any staff abuse toward other patients, he stated he has seen B C be hit and pushed so hard that he fell to the ground.

9. L G - has been a resident in ASU for 10 months. He responded negatively to all questions related to staff abuse. When questioned specifically about his reaction to having cold water splashed on him by staff to awaken him in the mornings, he stated that he did mind this. He feels staff treats him kindly.

V. ADMINISTRATION OF ADOLESCENT UNIT DID NOT INVESTIGATE; HUMAN SERVICES POLICE HAVE TAKEN NO FURTHER ACTION.

8. Letter to Seargent Hydock of the Human Services Police re abuse in adolescent unit.
9. Letter Jerry Bolek, Unit Administrator, Adolescent Services Unit, Trenton Psychiatric Hospital re abuse in adolescent unit

State of New Jersey

DEPARTMENT OF THE PUBLIC ADVOCATE
DIVISION OF MENTAL HEALTH ADVOCACY
MERCER COUNTY REGIONAL OFFICE
CN [illegible]
TRENTON, NEW JERSEY [illegible]

Joseph H. Rodriguez
PUBLIC ADVOCATE

Laura M. LeWinn
DIRECTOR

TERRY A. COBLE
DEPUTY PUBLIC ADVOCATE
TEL. [illegible]

October 24, 1984

Sergeant Paul Hydock
Human Services Police
Trenton Psychiatric Hospital
P.O. Box 7500
West Trenton, New Jersey 08625

Dear Sergeant Hydock:

Enclosed are the affidavits concerning abuse of minor patients who reside in the Admissions Cottage of the Adolescent Unit at Trenton Psychiatric Hospital, known as Kennedy Cottage. As you can see, the affidavits allege that on two separate occasions the program coordinator, L W , took an adolescent patient into a seclusion room, removed his own jacket and the contents of his pockets, and challenged the child to fight him. In one case it is alleged that he threatened to knock the child's teeth out and to beat him so that no marks would show. In both cases it is alleged that he threatened to beat the adolescents severely if they did not fight him. Further, in one case, L W allegedly hit the child and grabbed his face, saying repeatedly "you look in my face when I talk to you." The affiants also state that they have seen L " hit patients and use unnecessary force against them. They allege that he threatened one patient that he (W) would file a criminal complaint against him, even thouth there was no basis for such a complaint.

Another adolescent, a present resident of the cottage, testified to similar behavior on the part of L W and of other staff. From our other interviews, we also learned from a current resident in the cottage that on one occasion, Mr. Wilson stopped a boy who was chasing another patient by grabbing him around the neck and choking the child so hard that he lost consciousness. Two other staff members* to whom we spoke verified that they had witnessed this incident.

In addition to accusations against L W , the affidavits contain reports of assaults by other staff members. Current residents of the cottage to whom we spoke told us that staff pull patients by the hair, and have deliberately struck patients' heads against the floor. We have reports that staff slap, punch and kick patients when breaking up fights. One child witnessed a staff member hold a

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*These staff are professionals assigned to that Cottage.

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patient while another staff member, a Mrs. B , pulled out a clump of the child's hair. Another child told us that a staff member named "V ·" pulled him across the room by the hair several times and there are witnesses to this. Still another child stated that staff do not intervene when other patients try to beat him. We are told that one child in the cottage in particular is allowed to be victimized in this way. (Some of the above information was elicited during follow-up interviews by Laura Roth with patients when Officer Dlugokenski was not present.) All patients we interviewed who are still living in the cottage were very frightened to talk to us-- Officer Dlugokenski can attest to that -- and would not let us use their names because they fear reprisals from staff. The three affiants were willing to sign statements only because they were on the verge of discharge.

We are extremely concerned about these reports of staff abuse of patients which have now come from a number of adolescents as well as staff. We have reason to believe that the brutalizing of these children continues unabated. We have reported the allegations contained in these affidavits to the Division of YOuth and Family Services and are sending this information to Mr. Carchman.

We believe that an inquiry should be made immediately into these matters. Please call me or my colleague Laura Roth as soon as you receive this letter to advise us as to how you plan to proceed. Finally, with regard to your recent phone conversation with Ms. Roth, we trust you will not release these affidavits to any Hospital administrator or staff member as your own policy dictates.

Thank you for your prompt attention to this matter.

Very truly yours,

Carol J. Sands

Carol J. Sands
Assistant Deputy Public Advocate

Enclosures
CJS;vmg

State of New Jersey
DEPARTMENT OF THE PUBLIC ADVOCATE
DIVISION OF MENTAL HEALTH ADVOCACY
CN 850
TRENTON, NEW JERSEY 08625

JOSEPH H. RODRIGUEZ
PUBLIC ADVOCATE

LAURA M. LE WIN
ACTING DIRECTO
TEL. 609-292-178

October 24, 1984

Jerry Bolek, Unit Administrator
Adolescent Services Unit
Trenton Psychiatric Hospital
Sullivan Way
Trenton, New Jersey 08625

Dear Mr. Bolek:

In late September several allegations of staff abuse were reported to our office by male Kennedy Cottage residents. Shortly thereafter, we relayed this information to you, Human Services Police, and Frank Cuomo, Acting CEO, (as well as to DYFS) and received permission from you and Mr. Cuomo to interview all male Kennedy Cottage residents. Our office, along with two representatives from your Department* spent the afternoon of October 12 speaking privately with each Cottage resident.

The result of this inquiry presented a picture of widescale staff abuse of the adolescents in Kennedy Cottage. Many allegations made by children during the interviews are similar in nature to the allegations we first received in late September.

As you know, we obtained several affidavits based upon the complaints first received by our office. Since that time, we have been granted permission by the affiants involved to release their statements to the police only. We are, therefore, unable to submit copies of these affidavits to you. We can, however, provide you with a summary of the allegations received from all of our clients, including those who signed affidavits. We trust that this will provide ample support to justify appropriate administrative action on your part.

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* Both the police officer and Daryll Jones, a staff trainer, are employed by the Department of Human Services.

The following, then, is a summary of the allegations made by our clients:

A. Regarding L. . W , Program Coordinator:

1. Multiple criminal assaults against patients including choking and slapping patients as well as throwing patients;

2. Verbal threats of severe bodily injury to several patients;

3. Verbal threat to knowingly file a false criminal charge against a patient;

4. Repeated verbal abuse, especially name calling of patients (i.e., "faggots, creeps, punks, assholes");

B. Regarding Other Non-Professional Staff - (Day and Evening Shifts):

5. Allegations by five (5) children of criminal assaults. A total of seven (7) patients claim to have witnessed criminal assaults by staff against patients. These staff assaults include slapping, hitting, punching, and hair pulling;

6. Repeated threats by many staff to withhold particular Rights of Patients (N.J.S.A. 30:4-24.2) as punishment for misbehavior;

7. Repeated threats to summon Mr. Wilson as a means to threaten and punish patients for undesirable behavior;

8. Seven (7) patients complained that staff often use excessive force when applying restraints and appeared to be purposely hurting patients;

9. Several patients complained about:

a) Lack of therapeutic programs during the day (for those not attending school) and in the evenings;

b) Lack of recreation time and time out-of-doors;

c) Feelings of imprisonment which heighten tensions between patients and patients and staff;

d) Pervasive "nasty" and non-assisting attitude of staff.

Thus, in addition to criminal complaints against Mr. W. and other staff, patients complained of feeling physically threatened by staff and generally abused by them. Irrespective of the outcome of the criminal investigation which the police will pursue, we recomend the following administrative actions:

(1) Continue to segregate Mr. W from patient contact pending the outcome of the police investigation.

(2) Similarly, as an initial step, transfer of several day and evening shift staff from Kennedy Cottage to other cottages in order to dilute the pervasively hostile staff attitude toward patients. This would be a signal to staff and patients of the administration's concern -- a symbolic gesture that should be more directly addressed by you in the near future pending the outcome of the police investigation.

Please advise us immediately as to what steps, if any, you have taken or plan to take to address the issues presented above, including the programmatic issues. In the meantime, our office will remain available to these Kennedy Cottage residents and continue to notify you if other complaints are brought to our attention.

Very truly yours,

Carol Sands

Carol Sands, Esq.
Assistant Deputy Public Advocate

CS:jd
cc: Frank Cuomo, Acting Chief Executive Officer
Laura LeWinn, Acting Director

VI. EXCESSIVE USE OF RESTRAINT AND ISOLATION OF ADOLESCENTS

10. Medicaid Periodic Medical Review of Trenton Psychiatric Hospital for 1984

State of New Jersey
DEPARTMENT OF HUMAN SERVICES
DIVISION OF MEDICAL ASSISTANCE AND HEALTH SERVICES

ADMINISTRATIVE OFFICES
QUAKERBRIDGE PLAZA—BUILDING 7 & 8
QUAKERBRIDGE ROAD
TRENTON, NEW JERSEY [illegible]

ADDRESS REPLY TO
CN-712
TRENTON, NEW JERSEY [illegible]

609-292-7097

September 6, 1984

SEP 7 1984

Carol J. Sands, Esq.
Assistant Deputy Public Advocate
Departmetn of the Public Advocate
Division of Mental Health Advocacy
Mercer County Regional Office
CN-850
Trenton, NJ 08625

Re: Medicaid Periodic Medical Review

Dear Ms. Sands:

Pursuant to your request, enclosed please find a copy of the 1984 PMR for Trenton Psychiatric Hospital.

Very truly yours,

Robert M. Liwacz

Robert M. Liwacz, Esq.
Chief, Bureau of Research
and Development

RML:dg
Enclosure

c Raymond B. Reinhart, M.D.

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STATE OF NEW JERSEY
DEPARTMENT OF HUMAN SERVICES
Division of Medical Assistance and Health Services
Bureau of Mental Health Services

PERIODIC MEDICAL REVIEW OF TRENTON PSYCHIATRIC HOSPITAL ON JUNE 28, 1984

Mandate:

The Division of Medical Assistance and Health Services as mandated by the Social Security Act, as amended, Sections 3(a)(4)(i) and (ii), 1603 (a) (4)(i) and (ii) and 1902 (a)(20) and (26) appointed a team consisting of two physicians (certified psychiatrists), one registered nurse and two social workers which conducted a Periodic Medical Review at Trenton Psychiatric Hospital. An exit conference was held on June 28, 1984.

The thrust of the regulations issued by the U.S. Department of Health and Human Services, Social and Rehabilitative Service, is to assure that each patient receives the optimal care for his condition. Thus great emphasis is placed on being certain that the patient requires hospitalization; that there is a rational plan for treatment; that the plan is being followed or modified as indicated and that every effort is being made to reduce dependency and to develop self-care capabilities.

Introduction:

The following report consists of two sections: the under age 22 population and the over age 65 population.

The Periodic Medical Review Team wishes to thank the staff of Trenton Psychiatric Hospital for their cooperation during the review.

Adolescent Unit - Total Population - 25

1. Certification of need for admission was satisfactory.

2. Recertification for continued stay was non-compliant in nine cases due to going beyond the sixty days or recertifying at thirty day intervals at the end of the year.

3. Plan of Care was not developed within the fourteen days of admission in four cases.

   Many deficiencies were found in the review, modifications, monitoring and content area.

   In seventeen cases either the full team was not present, minutes of the meeting were absent and/or they did not always indicate the youngster's degree of participation or review with the client if he/she was not present. In some instances, the primary therapist's note was combined with/substituted for the team notes.

In almost half of those cases reviewed the plan of care summary (team reviews) entered in the progress notes were found to be too brief and non-specific in nature.

Recommendation: In addition to outlining the extent and level of participation by the client in the team meetings, these summaries should contain itemized information relative to progress toward goal attainment and information on any staff conflict/disagreement relative to the implementation of the team treatment plan.

Level of functioning was not always done; titles of the evaluators were missing and a current form was not always on the record.

4. The Discharge Planning Form was incomplete in several instances. In one instance, the client was out on interview and there was no documentation of the results of the interview until discharge.

Approximately half of those client cases reviewed would benefit from placement in a less restrictive environment. This fact was often documented by the TPH staff and frustration was often expressed toward the length of time taken by the referring agency in securing alternate placements.

Recommendation: It is the opinion of the reviewers that the staff of TPH Adolescence Unit is doing everything possible, within their control, to attain client placement in a less restrictive environment as expeditiously as possible.

5. Social service progress notes were always found at least quarterly in all cases reviewed. Content was generally very good overall and excellent in some cases. However, several cases did not indicate adequate family contact and, in those cases where the social worker was assigned as primary therapist, social service notes were not entered, as such, and content did not always address social service information of a more non-clinical nature.

Recommendation: In those cases where the social worker is assigned as primary therapist, it is recommended that another social worker retain the more non-clinical social service functions (liaison, discharge contacts, family contacts non-clinical and DYFS coordination). If this is not possible due to staffing considerations, then the social worker, when assigned as primary therapist, should enter separate notes on a minimum of a quarterly basis addressing those issues of a less clinical social service nature.

6. Medical Services

Physician's Orders - Nearly all records reviewed were compliant. Orders are being continuously reviewed and updated. In one instance, a discharge order was given verbally and never countersigned. An endocrine work -up and thyroid function tests were recommended on admission, but no results were found.

Progress Notes - The progress notes were compliant. The content has improved over last year, are being done on a thirty day basis and are descriptive of the condition and needs of the client.

Tests, Observations, Consults, etc. - Some deficiencies were found. Laboratory work is being done. There appears to be a lack of follow through on a persistent low CBC with the resident on multi vitamins and an occasional absence of Aims test. Dental care is being provided. A surgical consult was requested and the team could not determine why. The interdisciplinary team requested a neurological consult which, along with a psychomotor test, had been recommended by the physician at Brisbane and results could not be found. One youngster was known to have worn glasses previously and did not have them upon readmission, but it could not be determined if there was follow up.

Psychiatric consultation, evaluation and intervention is ongoing. In one record, there was documentation indicating a difference of opinion between the psychiatrist and psychologist regarding placement of the youngster in a less restrictive setting. The resolution of this problem could not be found.

Physical examinations - All records contained current physical exams completed annually. The review of systems was comprehensive and descriptive of the physical developmental level.

7. Dietary Services - Review of the records indicate the need for more involvement by dietary services. There is also a need for collaboration between dietary, medical and nursing services relative to the nutritional needs of the adolescents. Fifteen cases indicated a need for direct intervention. Of this number, six were evaluated, one record contained a comprehensive note and the remaining eight, who were gaining weight, including one young lady who requested a 1500 calorie diet from the physician, were not evaluated by the dietician.

In one instance the physician did accept the dieticians recommendations, but in another, they were not even acknowledged.

The interdisciplinary team also needs to examine the use of snack type food as a positive reinforcer.

8. Rehabilitation Services - The occupational therapy services department is to be commended for the thorough screenings and evaluations performed. Documentation of direct therapy services is excellent. The recommendation for a Home Program is an indirect service and should be addressed either by the caregivers who assist in the implementation with the youngster or a brief consultative note by the therapist.

9. Speech and Hearing Services - The screenings evaluations, treatment and documentation is excellent and the department is to be commended.

10. Special comment on use of mechanical restraints/seclusion - Both the nursing and social service components of the PMR team conferred and agreed that mechanical restraints appeared to be used too frequently and without the use of alternative methods of behavioral control being thoroughly explored. In addition, documentation of the use of mechanical restraint was inadequate and not properly noted relative to frequency and duration of use.

The use of mechanical restraints/seclusion should be viewed as the last option taken relative to controlling clients with behavior problems.

In the repertoire of professionally acceptable methods of controlling problems and behavior, counseling, privilege restrictions, and the implementation of formal behavior modification programming should preceed the use or application of mechanical restraints.

There did not appear to be efforts made to differentiate between what is normal and abnormal adolescent behavior; no apparent effort to distinguish normal and extremes of "acting silly". When 1:1 counseling/observation was the chosen method of intervening, there was no staff to do it.

Level dropping was not consistent - the team suggested 1:1 when one resident became withdrawn, yet when she withdrew and needed the 1:1, her level was dropped. In only one instance the primary therapist documented the use of contracts with the residents.

It is strongly recommended by the PMR team that mechanical restraints be used in a more judicious manner. Documentation of the use of mechanical restraints/isolation should be summarized in the primary therapist's progress notes. Content should include: frequency of use since last progress note entry, duration of each usage, and the reason for the usage of these methods. In addition, the primary therapist should clearly and specifically state those alternate methods of controlling problem behavior that were attempted preceeding the use of mechanical restraint/isolation.

11. Nursing Services were deficient primarily due to the lack of RN involvement in the management of staff and their implementation of the clients' treatment plan.

Nursing services has the responsibility to ensure that the adolescent clients are provided sufficient knowledge/supervision in personal care, ADL skills, physical and emotional outlets to promote healthy growth and development.

Non professional staff need the supervision/monitoring/teaching relative to the implementation of the plan. There is a noticeable absence of counseling/teaching of personal care, nutrition, sex education, health, 1:1 counseling/observation and most importantly the guidance of staff in determining the need for restraints/seclusion.

Nursing assessments are not being documented as being done, thus, the health needs are not identified.

Nursing care plans are integrated into the treatment plan. In some instances, the physician has had to develop a plan of care for those areas considered to be in the nursing realm.

Nursing progress notes were deficient in the majority of the records reviewed. The LPNs and non professional staff are documenting their observations, some of which are very perceptive. The RN is not doing a comprehensive evaluation based upon her own assessment of the resident's progress or lack of as well as the observations of direct care staff. Several evaluative notes found within the year were thoughtfully and well written.

12. Utilization review was non compliant due to the absence of documentation, the review being performed by the same person in charge of a ward and not by an RN.

    The utilization review by a skilled professional will ensure proper admission and medical care appraisal of appropriate health services to the client.

SUMMARY:

About one-third (six) of those cases reviewed were interviewed in group. The remainder were interviewed by Medicaid nurse reviewers. It appeared that the clients at TPH Adolescent Unit are generally well treated by a professional and caring staff. Documentation of programming usually met or exceeded PMR requirements. Discharge appeared as an active consideration throughout the clients' stay and the use of PNA funds was documented on a periodic basis. Progress notes entered by team members (O.T., recreation, rehabilitation services) were of very good quality overall. The concept of "active treatment" was found as being addressed on an ongoing basis in the majority of those cases reviewed.

Recommendations:

(1) In most of those charts reviewed only three to five months of progress notes were found in the chart though the remainder were available to the reviewers. It is strongly recommended that a minimum of six months of progress notes be retained in client charts at all times. The primary reason for this is to give new and/or transferred staff an opportunity to get a complete picture of the client's progress for which he/she is assuming responsibility.

(2) Increased availability of clean, properly fit clothing.

(3) Improve communication between Education and Interdisciplinary team relative to health problems (example: suspecting child of being dyslexic - should be referred to physician who in turn would make proper referral for diagnostic purposes).

(4) Suicidal threats be referred immediately to professional person for evaluation.

(5) The legal record should not contain progress notes written while the resident was on leave.

OVER AGE 65 POPULATION - 77 CASES

UNDER AGE 22 POPULATION - 8 CASES IN ADULT UNITS

The majority of the over 65 population was found mainly in the Raycroft building. /

1. Recertification for continued stay was deficient in eighteen adult and three under age 22 records due to going beyond the sixty days and recertifying at thirty days at the end of the year.

2. Plan of Care - There were thirty-four deficiencies in the over 65 group and five in the under 22 group in the review and modification of the Plan of Care. Either the full team was not present, team notes were absent and the presence or absence of the resident was not always indicated or the degree of participation was not noted.

   Improvement was found, however, in many areas of the plan of care and implementation and this was due to the use of a new format where goals are clearly itemized, stated in specific and behavioral terms, target dates are set and responsible staff members are assigned. Program barriers were identified in all cases reviewed under the rehabilitation services initial assessments which were completed and reviewed by the Staff OTR. Discharge was clearly stated as a primary objective in most cases reviewed and was either deferred (where appropriate) or pre placement criteria toward discharge was spelled out.

   The level of functioning was not always done quarterly and the current copy was not always in the record. It appears to have not been used in the planning of care.

   New problems and diagnosis were not on the care plan though they were addressed in the progress notes.

   Goals were not specific and measurable and at times were unrealistic when compared to the client's condition.

   Plans of care were absent in the Medical/Surgical Unit. Programming was suspended without any justification and/or specifying documentation. It also appears that team meetings were not being held. This is a repeat deficiency.

   Recommendation is made that plans of care be re-evaluated and updated when a patient moves from one section to another so they accurately reflect what treatment the client will receive in the new section.

3. Dietary Services were deficient in the majority of cases reviewed because nutritional assessments are not being made on patients at risk. Snacks are not being given on a regular basis to all residents. Medical, dietary and nursing services should collaborate for the resolution of particular problems. This is a repeat deficiency. However, improvement has been made in the content of the meals (including milk) served.

4. Other Services - Active programming has increased off the ward. Occupational Therapy services provide horticulture, movement and music therapy as well as group activities. Documentation of evaluations, progress and client involvement is of good quality.

   Although documentation of ward/off ward activities has improved, observations indicate the level of activity remains very low for some residents and moderate, at best, for others. Progress notes (rehabilitation services) addressed objectives as stated in the plan of care in most cases reviewed and related activities were appropriately programmed.

   An increase in aggressive behavior of some confused clients has been noted due to continuous stimulation in a constant round of activities. This should be closely monitored.

   It was observed that a formalized program of Reality Orientation was provided off the ward. It must be emphasized that Reality Orientation, Remotivation and sensory stimulation program originated with and remain basic nursing functions, which can be integrated into the client's activities of daily living by nursing staff.

   Ward activities continue to be lacking. Clients walk about aimlessly or sit in chairs in halls, rooms, dayrooms without communication. The non ambulatory or debilitated residents are not getting any or very little services.

5. Utilization Review is almost totally non-compliant. They were not being performed in ninety days. They were not being done by a registered nurse who has the expertise to determine appropriateness of admission and services.

6. Social services were found not to be periodic (minimum quarterly) in almost a quarter of those cases reviewed. Some additional entries (more than quarterly) were found indicating court involvement, family contact, and contact with potential discharge facilities and liaison workers. Some improvement was noted in social service plans, however, these plans were too vague and general in about one fifth of those cases reviewed. Discharge potential/plan was addressed in almost all of the social service notes reviewed. Social functioning was occasionally addressed relative to behavior as a barrier to placement or disruptive behavior interfering with patient programming. PNA was addressed in a consistent manner concerning the use of patient funds for personal needs items and the use of the trading post.

   Increased preparation of the patient relative to discharge could be improved (counseling, field visits, etc.). However, improvement was noted concerning family contact (discharge) and contact with community services (nursing homes, BTS, CMHC liaison). The Bill of Rights was not found signed by the patient in about one quarter of those cases reviewed. In many of these cases no attempt had been made to review the Bill of Rights with the patient for over five years. After initial administration, re-attempts should be made for those patients who become better able to understand its contents.

7. Medical Services

Physician's Orders were compliant in all but two cases. Nurses' notes indicated Navane ordered and given but the order was not found. Orders were overdue in one case.

Physician's Progess Notes were deficient in thirteen cases in the over 65 population. These were due primarily to an absence in one month or not done in 30 days. Content, including the evaluation of the client's progress relative to the medical care plans, has improved tremendously.

Physical Examinations were done annually. Clients' refusals were well documented. Aims were done consistently.

Psychiatric Evaluations were done yearly on all but one case reviewed. It could not be found in the record.

8. Nursing Services continue to be totally non-compliant in the implementation of the nursing care plan. The problems from last year's Periodic Medical Review have not been corrected and seem to have become more widespread.

Nursing assessments are not being done on admission or periodically as problems appear thus total nursing needs are not being identified.

Nursing Care Plans - The nursing care plan has been incorporated into the interdisciplinary treatment plan. They are almost totally deficient. The Medicaid nursing staff questions whether the nursing intervention is really developed by a registered nurse. All of the clients' problems/needs are not on the plan and thus are not being managed though they are identified in the notes.

The nursing needs component is identified under social functioning (of the new D.O.S.P. format) rather than personal care or ADL needs which are needed for basic healthy living. They impact upon social functioning but paramount are the health problems generated from the lack or non use of ADL skills.

The methods of intervention do not describe nursing measures but only the implementation of the medical regime.

The RN is legally responsible for the supervision of the daily activities of non professional staff which includes the provision of consultation to the LPN. The RN in this institution is seriously jeopardizing her license by not adhering to the standards of practice emanating from the legal definition of nursing practice in this state. The shortage of professional as well as non professional staff poses serious legal, ethical and moral questions to the nurse reviewers of the Medicaid team. In one instance we observed 2 employees caring for 31 patients.

Nursing care is grossly non-compliant. The implementation of the medical regime is not adhered to. Frequently medications were not being given/signed for; insulin was administered prior to a fasting blood sugar; absence of clinitest and seizure records; no seizure follow up; no evidence of Foley catheter care; pulses not always checked prior to administration of digitalis; vital signs and intake and outputs not being recorded properly; therapeutic supports being used without proper documentation of periodic release and activity time.

There is an absence of monitoring/assistance at meal time. Trays are placed on clients' laps. Bibs are not used so clients walk about with food stains down the front of their clothing. Sandwiches are left whole and unmanageable.

Inconsistency is not addressed. There is no evidence of active B&B programming, many of whom would benefit. Patients were observed sitting with their bare feet in urine puddles. Pica problems not addressed.

Decubitus care not addressed relative to size, depth, drainage, location and response to treatment. Aides have been observed applying prescribed medication.

Patients are disheveled, untidy, unkempt. Males are shaved only once weekly. With this population there is an unusual lack of eyeglasses or dentures, community clothing, combs and wash basins. Lack of self care programs. The team questions whether non ambulatory patients are ever given tub baths or showers. The second floor lounge actually smelled after the residents left a music program.

Restorative nursing programs have been removed from nursing care. Reality orientation is a daily ongoing process between staff and client. Sensory stimulation is incorporated into activities of daily living. Remotivation is an ongoing process for the patient being "encouraged" towards maximum independence.

Patients are observed in different stages of lounging positions from which they appear not to be repositioned or ambulated.

Progress notes are devoid of documentation of patient management by the registered nurse. More recently RNs are writing evaluative notes, but must improve their skills. There has not been one instance in which the intervention was changed or another method tried to reduce or rectify a potentially dangerous situation.

There is no evidence of active, restorative/rehabilitation nursing measures. The non professional staff were caring and kind but need supervision and direction from the registered nurse.

COMMENTS/OBSERVATIONS:

The premises of Trenton Psychiatric Hospital Adult Unit were noted to be exceptionally clean and well cared for on all occasions reviewers had to enter and exit the wards. Privacy and environmental considerations were also noted as good relative to the number of patients per room and bathing and toileting procedures (use of screen). The staff were very cooperative with this reviewer and asked questions and sought feedback on numerous occasions. The reviewers' overall impression is that there has been notable improvement in the social service component area of patient care over last year's review. Finally, problem areas that persist and that should be addressed over the forthcoming year include: the level of on/off ward activities, progress note summarization of the plan of care by the review team, correction and updating of reality orientation boards, preparation of patient for discharge and the administration of the patients' bill of rights.

Progress notes were seldom found in the chart for more than 4-5 months previous. It is recommended that a minimum of six months progress notes be retained in the chart and that fragmentation summaries be entered for all relevant disciplines (medical, nursing, social work, and rehabilitation services).

The ward charts are now arranged alphabetically per last year's recommendations.

Improvement has been made in medical progress notes and off ward programs.

Finally, nursing services have deteriorated to such a degree that care does not meet minimally accepted standards . Many of those patients reviewed were assessed as not receiving the level of care to promote optimal functioning. This was due to inadequate staffing and waiting lists for therapies and in part to resistance/refusal to participate in programming by the patient. Continued attempts should be made and documented by the staff to involve these patients in programming and various attempts to deliver alternate programming should be persued. Almost half of those patients reviewed (over 65) at TPH would benefit from alternate placement (primarily nursing home placement).

Raymond B. Reinhart, Jr. M.D.

Report submitted by: Raymond B. Reinhart, Jr., M.D.

Title: Chief, Bureau of Mental Health Services

Date: August 15, 1984

jcs

TRENTON PSYCHIATRIC HOSPITAL - PMR REVIEW 1984 - ADULT UNIT

Social Service Component

Residents - 85

Due to the nature of last year's PMR report and the degree of improvement noted by the social service reviewers for the 1984 review year, a comparative chart is being presented in addition to the narrative report. The following chart list the quality that was cited last year, the degree of improvement, and the appropriate symbol.

1983	1984	Improve Same Regression
Area of Citation	Degree of Improvement	Symbol
Plan of Care- Unclear and unspecific	Considerable Improvement	↑
Plan of Care - Not written in behavioral terms	Some Improvement	↑
Chart information cluttered and difficult to read	Considerable Improvement	↑
Summary of plan of care did not identify progress or lack thereof	Same	→
Barriers not adequately identified	Considerable Improvement	↑
Level of functioning not consistent (lacks raters name and title)	Some Improvement	↑
Discharge plan not being done by review team	Some Improvement	↑
Criteria for discharge unclear	Improvement	↑
Reality orientation boards out of date	Same	→
Ward activities totally lacking	Some improvment in the area of documentation-low to moderate level of activity overall, as observed	↑
Progress notes do not contain specific goal or activity being addressed	Considerable Improvement	↑

1983 Area of Citation	1984 Degree of Improvement	Improve Same Regression Symbol
Social Service notes not quarterly with additional entries as indicated	Some Improvement (9 of 40 cases reviewed not found quarterly)	↑
Insufficient contact with family, when involved	Some Improvement	↑
Social service plan not adequately addressed	Some Improvement	↑
Discharge plan/potential not adequately addressed	Considerable Improvement	↑
Social functioning not addressed	Improvement	↑
PMA documentation poor	Improvement	↑
Discharge Planning:		
Preparation of patient	Same	→
Contact with family	Improvement	↑
Appropriate referrals	Improvement	↑
Bill of Rights signed by patient	Regression (no attempts of re-administration after initial)	↓

ITEM COMMENTS

Social Service Assessments - Very good to excellent quality overall.

Psychology Evaluations (recent admissions) - Very good overall.

Rehabilitation Services - Most progress notes very good (some excellent).

Plan of care summaries (team review) - Although too brief overall - frequently contained information regarding level of involvement of patient at the meeting and his/her participation in plan - very good.

O.T. documentation in progress notes sometimes found every two weeks - very good.

Under stated objective of social functioning - social worker seldom listed as responsible staff - Why?

Assessments - O.T., Movement Therapy, Music Therapy - Documentation very good quality overall.

Attendance

Jessie [illegible] Rep Medicaid
Ed Raymond MSW
[illegible] M.D. Med Services
W.J. [illegible] AHP
Terry Evans Administrator
Mary Robinson Liaison Coordinator
[illegible] MSW · Assistant Unit Administrator Adolescent
Jean Kelty ETU
Jim Detty, Social Services
Richard Golden Dir of Rehabilitation Services.
S. R. Chhatwal, M.D., Raycroft Section
N. Shetty M.D. acting medical director.
Katrina Biggs-Awani Unit Administrator
Janny Wilson ADON - Raycroft Complex
Jane B. Page S.W.S. II - Raycroft Complex
Marie Anton Prog. Coord, Hudson Sect
Claire Dunbar "
Carol Jones Raycroft Complex Administrator
Claire Henry Infection Control Coordinator
Edna Volpe Hay Raycroft Complex P.C.
[illegible] Adol. Services - Lincoln Complex
[illegible] King Cottage, adolescent section
Susan R Mallard. SWS II - Div - Parker
Rose Marie Saastender, RN UR Coordinator
Val [illegible] Prog. Cond. Adolescent

ATTENDANCE
TRENTON PSYCHIATRIC HOSPITAL PMR
JUNE 28 1984

Gerald Bolek - Adm. Services - Lincoln Complex
Lattie Cundy - Dix-Parker Complex
Edna Volpe-Hay Raycroft Complex
Claire Henry - Infection Control Coordinator
Carol Jones Raycroft Complex Adm.
Claire Durkin Program Coordinator - Hudson Co/Annex
Marie Hinton Prog. Coordinator - Hudson Co/Annex
Jane B. Page - S.W.S II - Raycroft Complex
Carrie L Wilson ADCN Raycroft Complex
Audrey Holland Program Coordinator Drake Complex
Patricia Briggs-Harris Unit Administrator Drake Complex
N. Shetty M.D. acting medical director
S. Chhabria, M.D. Raycroft Section
E. Kerr, OTR Raycroft
D. Peters RN/ASON HN Raycroft
Frances Leiden HN Raycroft
Mary Freeman SON TPH
J. Kramer, AHA Marquand Circle Complex
Raymond D. [illegible] MD chief DMHS (medicine)
Philip Eckel MD medicine

Carolyn Alexander ADO11 ADOL. Lincoln Complex
LEON L. WILSON JR Prog. Coord. ADOL. Kennedy Cottage
Harriet Slotkin Med. Res. Admin
Frank M. Berall, ACSW Medicaid Social Work Supervisor
[illegible] MD Medicaid
Philip [illegible] MD Medicaid

VII. EXCESSIVE RESTRICTIONS ON LIVING CONDITIONS IN THE ADULT UNIT OF TRENTON PSYCHIATRIC HOSPITAL

11. Affidavit of Arthur Rosenberg 11a. Levels 7-14-84
12. Affidavit of Judy Weigand
13. Affidavit of David Buckley

14
a & b. Affidavits of D.M.
15. Affidavit of P.D.
16. Affidavit of M.A.O.
17. Affidavit of B.J.
18. Affidavit of E.M.
19. Affidavit of D.D.
20 Affidavit of K.P.
21. Affidavit of N.M.
22. Affidavit of J.N.
23. Affidavit of H.S.
24. Affidavit of D.D.
25. Affidavit of J.G.

(NOTE: Affidavits 14 through 25 were retained in the files of the Committee.)

AFFIDAVIT

STATE OF NEW JERSEY :
: SS.
COUNTY OF MERCER :

ARTHUR ROSENBERG, being duly sworn according to law, upon his oath deposes and says:

1. I am an attorney with the Department of the Public Advocate, Division of Mental Health Advocacy.

2. On July 30, 1984, with the assistance of Beth Barnes, Luis Fernandez and Kelly Kutler, Field Representatives with the Division of Mental Health Advocacy, a census of adults at Trenton Psychiatric Hospital, who have been court-ordered Discharged Pending Placement, was conducted. Included in this census were residents of the Mercer, Hudson, Tri-County and Geriatrics Sections, the Intensive Treatment Unit, and the cottages of the Transitional Living Unit.

3. The results of this survey show that of the one hundred and six (106) individuals who have been ordered Discharged Pending Placement:

(a) Only one (1) person has been given Level VI privileges, which permits that person to go off the grounds of the hospital without an escort;

11

BEST COPY AVAILABLE

(b) Only nine (9) individuals have been given grounds passes, permitting them free time on grounds, pursuant to their Level V status. Of these nine (9) individuals, five (5) are placed in the open cottages in the Transitional Living Unit. Two (2) of these individuals with Level V grounds passes are in the Mercer County Section (the only two (2) in Mercer with such privileges), and in both cases the court reviewing the Discharge Pending Placement specifically ordered that grounds passes be issued to these individuals;

(c) Thirty-one (31) individuals, or 29% of the DPP population are not permitted to go off their unit;

(d) Fifty-eight (58) persons, or 55% of the DPP population, are not permitted to go outside of restricted areas, such as the cafeteria and the gym;

(e) Ninety-nine (99) persons, or 93% of the DPP population, are residing on locked wards;

(f) Eighty-eight (88) persons, or 83% of the DPP population, are not permitted to go off the locked ward, by themselves, for any reason.

Arthur J Rosenberg
ARTHUR J. ROSENBERG

Sworn to and subscribed
Before me this 15 day
of [illegible], 1984.

[illegible]
NOTARY PUBLIC OF NEW JERSEY
[illegible]

LEVELS--July 14, 1984 Received from B.H., T.P.H. staff member

On this date in the Drake building, which houses Mercer county, Hudson county and other patients, the following numbers of patients were allowed freedoms as described:

1. Drake female admissions and acute patient ward.
   Noone on level 4 , 5 or 6--that means no patients could go outside unescorted, and since no escorts are provided, in sum, all patients are locked up.

2. Drake coed ward, W-1, former open unit prior to December 16, 1984.
   One person on level 5, with privileges to take walks alone outside between meal and bed times on the grounds of the hospital, but not to visit outside hospital grounds.
   Four patients permitted to go unescorted to activities they are assigned to, but not to take any walks alone or go to the canteen.
   All other patients locked in.

3. Tri-County Unit. Female Acute, W-9. Noone allowed to go outside. (No level 4, 5 or 6).

4. Male Acute unit, Tri-County, W-5. Noone on level 5 or 6 with grounds or community privileges. Four people allowed to go to therapy or activities.

5. Hudson E-301, Male acute. 3 on Level 4, may go to activities and therapy. Noone with grounds privileges.

6. Hudson E-203 5 may go to activities, Level 4. 3 have grounds privileges, but all were court ordered by Krol judges.

-Carol Sands

11a

3. In addition to witholding cigarettes from the patients, none of the patients, regardless of their level of privilege on the level system, were allowed outside this weekend. As a result of this situation, there were many incidents of patient-staff conflict. Two patients ended up in restraints, tied to the bed, and others were forcibly medicated with injections. Both patients and staff were continuously involved in incidents of arguments and conflict. Being locked up with nothing to do, and having smoking privileges removed, except for the unpredictable discretion of the staff made the residents very upset. This was the one privilege remaining and besides that everyone was totally imprisoned on the unit. A staff member, Ms. Bronson, told us this morning, referring to our discomfort without smoking, "I like watching people suffer." For some of the staff, the situation has lent itself to one where they are exercising power over the patients, to upset and discomfort them, and cause them to act out. The response is then to restrain and punish the patients. This also results in a drop in the patients' levels, so that future freedoms are prohibited to them, which their level would have ostensibly allowed.

4. During one of the abovementioned incidents, on Saturday evening of this weekend,(September 29th at 7P.M.), a hospital staff member, Mr. Kirkland, was arguing with an adolescent patient on my unit. He pushed the patient towards me and I pushed the patient back. Mr. Kirkland then came towards me and hit me on the left side of my head. I told him to leave me alone and not to hit me. He told me that he had a

right to hit me, when he desired to do so.

Sworn and subscribed before me this

2d day of October, 1984.

Carol J. Sands

Carol J. Sands, Attorney of the State of New Jersey

AFFIDAVIT

I, Judy Wiegand, being of full age do here depose and say:

1. I am currently a patient at Trenton Psychiatric Hospital on ward W-1 in the Drake Building, ordered here in the status of a Krol patient, since March 8, 1984.

2. I have in the past been trained and licensed as a Practical Nurse, and was employed in this capacity for a total of over seven years at Toms River Community Memorial Hospital, at Deborah Hospital and at Mac Guire Air Force Base Hospital.

3. On the ward where I reside, some patients are provided with no activities during the 14 hour day they are awake, between 6 A.M. and 8:30 P.M. at night. A few residents are permitted to attend occupational therapy for at most three times per week. This includes mostly sewing as an activity. Three patients including myself, who are considered convalescent have had a series of "exit training sessions." Also a few have been allowed to attend horticulture group a couple of times per week. Other than this, and A.A. meetings for a couple of patients, there are no activities. Most of the time there is nothing to do on the ward, and despite substantial doses of tranquilizing medications, patients are not allowed to sleep or rest in their rooms, which are always locked. Many patients therefore sleep in chairs or on the floor, which is frequently very unclean.

4. Other than when eating, patients are never allowed outside the ward. Recently all the patients were allowed outside

with the exception of myself. They were permitted to go into the fenced in yeard. I was told my level, Level 1 would dictate what privileges I was to have, however other patients, including a krol patient like myself who was on that level, were allowed to go out, while I was not. I have not breathed the outside air in several months except to go for an x-ray two weeks ago.

5. On weekends, the female patients are frequently locked by themselves in the corridor where their bedrooms are, without the presence of an attendant. The attendants then sit by themselves at the desk in the main part of the ward. There are not enough chairs, so some patients must sit on the floor, and it is very cramped. The television is broken so there is no distraction or activities to do. There are no books or games of any kind, except for one book shelf. On the men's side there is also one book shelf and a few games like chess, which most patients can't play. We are not allowed to use the Monopoly game because the staff say the pieces are dangerous.

6. Last Saturday, June 16, at 9 or 9:30 A.M., we were locked in the corridor without an attendant in the morning. The patients were not given their 8 A.M. medication until 10:30 A.M. and seemed restless. (I presently receive no medication). Suddenly a patient, H B hit another patient, T G , in the face. She had glasses on and her face swelled. The patients yelled for the attendants to come but they did not. The door was locked. Then another patient, M started to punch and kick T . T fell against the back of my chair and I was pushed forward toward the floor. M began

to kick T s. The beating went on for ten minutes but the attendants, Mrs. Y and Mrs. T still did not come. We all were yelling for them but they did not appear.

7. Finally Mrs. T . and Mrs. Y came and stopped the fight. Theresa had injured her hand and it seemed immobile, clenched into a fist. She has been throwing up daily, but despite this and the injury to her hand the attendants did not allow her to lie down. They did not give her ice for her hand or support it. She still has the hand unusable and has to sleep in chairs or in the isolation room to get a rest.

8. Several of the women on our ward, J G , T G , I B , J A . and another patient named A have been throwing up lately a great deal. The attendants never help them to clean up or take their vital signs afterwards. On one occasion, T had gone with her injured hand into the isolation room to sleep as had two of the other women. Some of them had trown up there and were too tired to clean it up. The attendant threw open the door and seeing them lying in the vomit, yelled "You lesbians clean that up!" and made them get the bucket. This is common for the attendants to be verbally abusive and to always make the patients clean up when they are sick. None of these women receive bed rest during the day despite their illnesses and heavy medications.

9. Recently I also had been vomiting and was tested for gastroenteritis. I also was not allowed to lie down after the attacks nor during my current bouts of pain on the side of my body. I also have endometriosis, which results in heavy flows each month

and a great deal of pain. I have had surgery several times for this condition but now receive no treatment or bedrest for the symptoms or the discomfort.

10. Two of the patients on this ward, I D and P M have regular epileptic seizures that are quite severe. Ms. M , who was recently moved to the adjacent ward, used to have weekly seizure. Sometimes she would seem to have one in reaction to verbal abuse and stress which the staff would give her. On one occasion, Mrs. T , an HST, refused to get her a sanitary pad when she asked for it. Mrs. T was verbally abusive to Ms. M Suddenly, M . M said she was going to have a seizure. Instead of trying to get her to lie down, Mrs. T did nothing. Ms. M fell back on her head and receive a huge lump on her skull.

11. When Ms M became incontinent during this seizure, Ms. T laughed at her. Ms. T did not move from her chair and only asked someone to get her chart. None of the attendant got up to help. Only the social worker P went to get ice for the patient's head. I helped to clean her up.

12. During the frequent seizures expereinced by Ms. D and Ms. M , so that they would fall on their heads, the attendants have never helped them to li down, to present them from biting or severing their tongues or to n them up afterwards. I have always had to help them. On one occasion, two other attendants, Mrs. E and Mr. F laughed when Ms. M became incontent during a seizure and had her legs exposed. They did nothing to help her though she had bitten her tongue and her mouth was bloody. I had to put a spoon in her mouth and turn her head to the side to prevent injury. Fianlly the staff did help her to lie down.

13. After their seizures, the patients are not permitted to lie down in their beds. Ms. K has been allowed to lie down only on a few occasions.

14. Usually medical complaints by patients are ignored by staff. In the case of J S, an older woman patient here, staff ignored her complaints of vomiting and pain for months following an amputation she received on her hand. Last Friday she had to be rushed to the hospital because her hand and her lips became purple and black.

15. The attendants on this ward regularly curse and yell at the patients. When the patients go to them with a problem they are always waved away with vituperative remarks. One patient, T G waited days to see the HSTs. Finally when she cried and kicked the ash can, they gave her a forcible injection of medicine.

16. I currently room with a Vietnamese girl named L T When she first came the attendants refused to feed her dinner. They said they would not bother to bring her food because she had not gone to the cafeteria (although I told them she was not allowed to do so because she was new to the ward). They treated her so abusively that she told me she would rather take poison than be here because they were so cruel.

17. The only activity I receive here is sewing in occupational therapy group once or twice per week and in the past, exit training meetings. I have no psychotherapy or other activities. I am not allowed to go 100 feet to the adjacent ward for art therapy, although I love to paint.

18. Since I have returned to this ward in March, all my mail has been opened before I have received it. It comes to me with scotch tape on it. I also have not received some of the mail sent me by my aunt and my sister. Bills and other materials have also

been missing.

I hereby attest that the foregoing statements are true.

6-26-84
DATE

Judy Wiegand
Judy Wiegand

Carole J. Davis
WITNESS

AFFIDAVIT

I, David Buckley, being of full age do here depose and say:

1. I am a patient at Trenton Psychiatric Hospital currently residing on ward W-1 of the Drake Building. I have been on this ward for over 33 days and am presently on Voluntary status.

2. During the day on this ward the patients are always locked up and are never allowed outside, except for one time during this month. We were at that time able to go out into a small fenced yard.

3. There are no games and no activities to accupy the time, except a chess game and a pack of cards. There have been two activities altogether in the month I have been here which are organized by staff. All we do all day here is to sit. If we pace, the attendants become angry. We are not allowed to nap in the day time and our rooms are locked unless the psychiatrist specially orders that we may be allowed to lie down.

4. When the patients go to staff with a problem (usually the staff present are attendants), they usually get verbally abused. There is a complete lack of sympathy for the patients among staff members. They allow sicker patients to be victimized by others, and allow some healthy patients to be abused by psychotic patients.

5. On one recent occasion a patient named Renee came up to the staff member, M . Y -, and asked her for medication for a headache. Mrs. Y yelled at her that she was busy and wouldn't be ready to give her the medicine until she was done with some other chore. R . went to lie down. I heard Mrs. Y say she was finished with her task and that she was angry that P had not waited at the desk for her to finish what she was doing so that she could receive the medicine. She threatened to write in R 's chart that she was a nuisance for asking for the medicine.

13
6

6. Mrs. Y then told her coworkers that she was going to give Renee a shot of meditation because she had not waited at the desk to receive the headache medicine.

6-26-84
DATED

David E Buckley
DAVID BUCKLEY

WITNESS

TPH patient care called repressive

JUL - 1 1984

First of a Series

By IAN T. SHEARN
Staff Writer

The emergence of "a new era" in treatment of the mentally ill at Trenton Psychiatric Hospital has arrived, the hospital's Chief Executive Officer Frank Cuomo proclaimed last week as he showed off the clean, attractive and modern wards in the recently renovated Drake Building.

Even though the state has invested some $12 million in modernizing the TPH facilities and has, for the first time since 1975, gained federal accredidation, there are some who warn that the new era is a trip into the past.

Those critics of the institution contend that by implementing new rules, the repressive hospitals of yesteryear are being rebuilt, stone by stone.

> 'Everyone has become terrified. We're working out of fear.'
>
> — TPH therapist

While arguing last Monday in an Ocean County courtroom for the release of a Drake Building court-committed patient, attorney Daniel Carluccio referred to conditions in his client's West-1 ward worse than those depicted in the popular novel and movie "One Flew Over the Cuckoo's Nest."

Carluccio called West-1 ward "an absolute snake pit" and put a psychiatrist on the stand who, in less dramatic terms, said the patient was receiving

• continued on A10, column 4

TPH

• continued from A1

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virtually no therapy, posed no harm to herself or others and should be released.

The judge agreed and the patient was released from the hospital to the care of her family.

The patient, Judy Weigand, had been committed to the hospital by the same judge after finding her not guilty by reason of insanity for the 1981 slaying of her mother.

Upon hearing the news of Mrs. Weigand's release, N.J. Human Services Director George J. Albanese, the ultimate boss of the state's five mental hospitals, vehemently denied the "snakepit" allegations, was "outraged" over Weigand's release and said so in a press release the next day.

IT WAS NOT the first time Albanese had been outraged by the actions of Judy Wiegand, hospital employees say.

The name Judy Weigand is well-known among the patients and staff of Trenton Psychiatric Hospital.

It was Mrs. Weigand who walked off hospital grounds last December and fled to the home of a relative in upstate New York. The escape did not go unnoticed by press around the state.

According to both hospital staff and members of the state Public Advocate's Division of Mental Health Advocacy, an immediate suspension of grounds passes throughout the entire hospital was ordered, combined with the [illegible] implementation of a newly formed, six-step "level system" of patient priviliges.

The level system, now being implemented at all of the state's mental hospitals, is basically a behavioral classification which dictates the extent to which each patient's freedom of movement is restricted.

Ms. Carol Sands, a Public Advocate attorney, contends that, as a result of Mrs. Weigand's escape, the unlocked doors of her open ward were locked.

"The level system actually went into *effect* [illegible] three months before, but when Judy Weigand escaped they suspended everyone's grounds passes, locked the doors and started threatening the staff. That's when it became repressive," said Terri Coble, managing attorney of the Mercer County office in the Public Advocate's Division of Mental Health Advocacy.

TPH'S CUOMO and his staff deny that ground priviliges were suspended or that the West-1 doors were locked because of Mrs. Weigand's escape.

"What we did was, we built in a better reporting mechanism (tracking and logging a patient's movements), we didn't change the system," Cuomo said.

In addition to the disputed degree of increased security, the hospital staff was threatened with suspension and termination if there were more escapes, according to several staff members.

"No one was threatened," Cuomo said.

"Accountability," is how Richard J. Wilson, director of the Department of Human Services' Division of Mental Health and Hospitals, terms it. "One of the main aims of the level of priviliging policy was to place greater accountability on (clinical) staff (to administration) in their making decisions with regard to restrictive environment," Wilson said.

Five employees have been suspended for "gross negligence" involving patient escapes since December, none of them involving Mrs. Weigand's incident, hospital officials reported.

"The chilling effect is pervasive," a hospital therapist said. "Everyone has become terrified. We're working out of fear. 'Don't embarass the commissioner' is what we work by, not what therapy can we give the patient," he said.

"When you make changes in a system, a system ongoing for many years, there will be people who will resist that change, for whatever reason that may be," Wilson said. "When you try to make staff more responsible, more accountable, there will be people who will be concerned about that. That's the way the system works."

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"THERE'S A VERY serious clash between security and treatment, and security's winning," said Public Advocate attorney Arthur Rosenberg. "And what's happeing now, over and over again, is security decisions are taking precedence over any clinical considerations," he said.

But besides staff members, "it's the pathatic, burned-out schizophrenic who suffers," the therapist said. "The level system is an atrocity. It's clear that we now only observe negative behavior and punish for that. The patients are regressing," he said.

"If you haven't made your bed, if you've smoked a cigarette in a non-designated area, if you haven't gone to therapy — nothing to do with your illness — you don't get promoted in the level system," said Ms. Coble.

"At this time last year, you'd see people outside, socializing and feeling better because of the sunshine," another hospital therapist said. "Now everyone just sits around on the wards doing nothing. The clinical treatment teams have very little decision-making power anymore; the administrators, the rule-makers are calling the shots.

"These days, therapy is the most unimportant thing going on at Trenton Psychiatric Hospital. I feel like a player in a black comedy," the therapist said.

"The buildings are new, but it's becoming an old asylum," a third therapist said.

When asked if he was satisfied with the quality of patient care at the hospital, Wilson replied, "I'm satisfied that the patient management at Trenton Psychiatric is adequate."

During a tour of the hospital conducted by Cuomo and his staff on Friday, many patients were seen swimming and lounging in the hospital swimming pool.

In the West-1 ward of the Drake Building — the ward on which Mrs. Weigand resided, the ward her attorney called a "snake pit" — there was not a single patient on the ward.

It was a clean, attractive ward with semi-private rooms. It resembled a college dorm more than a psychiatric hospital.

"Is this a snake pit?" asked Patricia Biggs-Swain, section chief of the Drake Building.

All of the patients had gone outside, into a fenced-in courtyard, and were soaking in the sunshine, something that staff and public advocate employees had claimed was never permitted. The patients are taken to the courtyard every day, Ms. Biggs-Swain assured.

But follow-up contact with patients on that ward yesterday revealed that, before Friday, the last time they had been out in the courtyard was three weeks earlier.

On Friday — the day this reporter visited the hospital — the West-1 patients were shocked to be told not only that they were going outside, but that they *had* to go outside, according to one lucid and articulate male patient on the ward.

"It just came out of the blue. Everyone had to go," he said.

The male patient, who said he has been at the hospital for more than seven weeks, said he is receiving and "no therapy at all."

Admitted for alcoholism and depression, the man said he had seen a psychiatrist once for a routine admission interview and has not received any counseling or therapy since.

"From what I gather from patients and staff, psychiatric care is going backward," said public advocate attorney Rosenberg. "The question that has to be asked is: 'Is it a hospital or is it not a hospital?' If it is not a hospital and the function is security — to keep people off the streets and that's it — then why don't they call it that and not go through the guise of calling it Trenton Psychiatric Hospital?"

Cuomo emphasized that in gaining accredidation, the hospital had to meet the strictest standards of paient care in the country. Some substandard conditions do exist in the back wards of some of the older buildings, he admitted. But the hospital is in the process of reducing admissions and closing down all of the older buildings. That process, part of the terms of accredidation, should be completed by July 1, 1985, said Cuomo, who has been chief executive at TPH for nine months.

Tomorrow: Part II — A look at federal accredidation of Trenton Psychiatric Hospital.

Senator Weicker. Ms. Sands is under subpoena, and I have to ask those who have been subpoenaed their questions immediately after their testimony. We will go to Maureen Kelly after that.

Ms. Sands, you state in your testimony that the Office of the Public Advocate is a cabinet level agency.

Ms. Sands. Yes.

Senator Weicker. Yet you say you were denied access to the records of violent incidents against the patients your office is created to serve. Would you please explain to me how that contradiction can exist and how it affects your ability to advocate for these patients.

Ms. Sands. Well, this situation has begun within the past year or so, and so far we have pursued negotiations to try to remedy the problem. We have not taken the next step yet. That is still in the planning stages.

I requested, I guess it was a week and a half ago, of the attorney for Division of Mental Health and Hospitals of the State to allow us access to the incident reports. We still have access to them at all other State hospitals except for Trenton Psychiatric Hospital. That is the only hospital that has withdrawn them from the medical charts.

But it is a great problem because it hampers our ability to investigate abuse because we feel that these are special reports that were made for the purpose of recording injury, unusual incidents, altercations on the ward between patients and staff or between patients. And without them we will not have complete information.

Senator Weicker. We have affidavits documenting serious incidents of abuse on the adolescent units. Since you are denied access to incident reports, how do you conduct your independent investigation and are you allowed to go onto the wards to interview your clients?

Ms. Sands. Well, the first notice that I had of those incidents was a call I got from a young man on the ward. We did not at that time have access to the wards. That is also a situation that has been going on for about 1 year or perhaps a little more.

The young man had to locate us by finding our number stuffed behind a radiator. And he called us and told us about some of the things that had been happening, the threats of assault, the threats of serious bodily injury. I came and I interviewed him and I interviewed other adolescents who were being affected by this situation, two other adolescents who claimed they had been assaulted and hit and threatened with serious injuries.

Senator Weicker. Assaulted by whom?

Ms. Sands. A staff member.

Senator Weicker. And the nature of the assault?

Ms. Sands. According to two of the adolescents they had been taken into the seclusion room by the staff member. He had taken off his outer clothing, his keys, and his pocket watch, and so on, and he had threatened to beat them up. In one case he had threatened to beat the young man up so that he would not have any bruises showing, so that he would be thoroughly beaten. And he did hit this young man.

In the other case it is a similar circumstance where he brought the young man into the seclusion room and removed his outer garments and threatened him that he was going to beat him up. In that case the young man sat down on the floor and he said he became very passive and he was able to prevent the beating.

But apparently there are allegations that this individual continued to threaten all the patients on the ward, hit other patients, and there was a situation—he was a senior staff member. It was a situation of tension and threats of violence that were frightening the other children. And when staff would, according to the children, want to discipline them or did not like what they were doing they would threaten to call this staff member.

And other staff were hitting children. Other staff were throwing water on children. The same staff member who hit and assaulted children also choked a child who became unconscious briefly in one incident. And the children were very frightened.

We eventually did interview all the children in that cottage with the help of a patrolman who we finally secured from the human services police after a couple of weeks of requests. That is one of the problems. It is very hard to get someone to investigate.

Even though I am not allowed on the wards, which is a problem as of now, I was able to interview the children. Now, the hospital administration within the last week has told us now they are going to let us have access to the wards, but that has not happened in effect yet.

Senator **WEICKER**. We have affidavits, internal memoranda, and investigative reports going back to 1980 documenting incidents of patient abuse, death by suffocation, and indignities such as lack of access to the outdoors and theft of patients' food.

I assume these matters were brought to the attention of the hospital administrators. What was their response?

Ms. **SANDS**. This was brought to the attention of the Commissioner of the Division of Mental Health and Hospitals at that time, the Deputy Commissioner, the Attorney General, several Deputies Attorney General, and the response was that they needed more evidence to have an undercover investigation.

We then supplied more evidence of patient beatings. There were two severe beatings that we submitted affidavits about. And we received a response that no investigation was deemed appropriate at that time. The matter was referred back to the hospital administration if they desired to make an investigation. But we do not know if they ever did perform one.

Senator **WEICKER**. Your testimony further indicates that many patients were locked on their wards 24 hours a day without any activities or programs. Can you tell me how this confinement affected the patients and staff on the ward?

Ms. **SANDS**. Well, it leads to overcrowding of the ward at all times during the day, and people were not allowed to go to therapy, and some therapeutic programs had to be closed because no one was allowed to go to them. What happens is if you keep children and adults locked up all the time, day after day, without ever knowing if they are going to get out—and some of them are convalescent; some of them are waiting to go to other placements; it creates management problem for children, for example.

Teenagers just become frustrated and they do normal things to try to deal with the situation. So there is a lot of resort to forcible medication, restraint, and seclusion to control them.

What happens is the emphasis is on control and management rather than treatment. And in the 8 months or more when no patients were allowed outside, staff were really upset because of the terrible management problems they were having to control all those people at once. They did not have the assistance of any therapeutic staff to help and that usually is the problem.

With grounds passes some patients can go outside and get a breather. They can go for a walk. But this was everyone on the ward all the time, and the staff were just faced with a terrible situation. As a result a lot of patients got sicker, they were telling us. Patients were regressing, losing sense of reality because the four walls got to them, just the fact that they never got even to go a few paces out in the sunshine.

They were not even allowed during that period to go to the window to get fresh air. Patients were rebuked severely for that. There was a paranoia.

Senator WEICKER. What do you mean they could not go to the window? What would happen if they tried to go to a window?

Ms. SANDS. A staff member would really get angry at them. The management focus became very extreme, and there was a situation of tension and anger even toward us during that period of time.

I mean, we would come on the ward and we would get a real lot of hostility, more than I have ever seen before on the ward, during that period of time from staff because they knew it was a terrible situation.

Senator WEICKER. You also stated that during an accreditation survey you observed activities and programs in which patients were participating, but after the surveyors left the activities disappeared.

Are you saying these activities were conducted for the benefit of the surveyors?

Ms. SANDS. I certainly never saw those activities before then or afterward.

Senator WEICKER. Are you aware of any other changes in Trenton Hospital routines or procedures during and prior to the accreditation surveys?

Ms. SANDS. One of the things that just seems most remarkable to me is that the patients are taken off the ward a lot when accreditation happens. People get bussed out for rides and picnics and they go outside. They are sent home for passes and there were a lot fewer people on the wards than when there is not accreditation.

Staff has told me other things, but I am not privy to actually witnessing other changes that might have occurred.

Senator WEICKER. Senator Simon.

Senator SIMON. Yes. You talk about attendants taking care of all those people at once. How many people are at the Trenton Psychiatric Hospital?

Ms. SANDS. A little over 500 right now.

Senator SIMON. And how often does this accreditation process take place, do you happen to know?

Ms. SANDS. I guess there have been two or three inspections in the last 3 years, as I recall.

Senator SIMON. And do you have any idea what percentage of the total budget—I am just using one institution now, but you can give me the total—of the Trenton Psychiatric Hospital is Federal funding?

Ms. SANDS. What percentage would be Federal funding. I know that the adolescent unit gets a great deal more Federal funding percentage wise than the adult would. The Medicaid funding would go mostly to patients under 22 and over 65. But I am not aware of the percentage.

Senator SIMON. But in any event, it appears that was the fear on the accreditation process. I do not want to put words in your mouth.

Ms. SANDS. Medicaid funding is contingent on the approval of the accrediting body.

Senator SIMON. And their fear was not the adverse public relations but the loss of funds?

Ms. SANDS. I am sure loss of funds is a concern and public relations is also a concern. I think the problem is that all these inspections are announced and they just do not reflect the every day, day to day workings of the hospital for that reason.

They reflect a special kind of preparation, and also what occurs is the accreditation focuses on paperwork and documentation of treatment rather than actual implementation of treatment. The accrediting body does not interview patients to find out if they are really getting the treatment that is in the paperwork.

So what happens is the hospital focuses on paperwork all the year and the staff spend their time in meetings, writing paperwork, writing treatment plans, not out with the patients; 99 percent of the patient's time is spent with staff who are not therapists or doctors.

Senator SIMON. If we were to have a small number of people who would just drop in at institutions around the country who would simply ask are patients getting fresh air, who would not give advanced warning that they are going to be dropping in, and they could recommend that Federal funding be dropped; that kind of thing might have a healthy influence on the New Jersey scene and presumably the rest of the Nation.

Ms. SANDS. I do not think the solution is to cut funding. That has not worked. When funding was cut the hospital had no incentive at that point to improve. Things did not get better. As a matter of fact, there is less funding available and it harms the patients. There should be a mechanism for more specific enforcement of the right to fresh air and treatment and therapy so that these changes have to be made by the hospital, instead of, as Mr. Ferleger said, merely promises being made to change and nothing else being done or total cutoff of fundings happening. There has to be some monitoring to make sure that the changes are made that are appropriate so people are really getting the treatment that is in the treatment plans and so that there is not some gap between the written word and reality.

Senator SIMON. And if I can just sum up then, if you were a member of the U.S. Senate—I do not want to wish that upon you, Ms. Sands—but if you were a member of the U.S. Senate, let me just make it an open ended question; what would you be doing to try to improve the situation in Illinois, in Connecticut, in New Jersey.

Ms. **Sands**. Well, in a situation of abuse what I would do is I would try to eliminate the conflict of interest that exists between the institutional police investigating a hospital in the same department that they are subsumed under.

There should be an independent, investigative agency that does not have that conflict of interest where they have to both protect staff from patients and then turn around and protect patients from staff because it is not working.

As you will see with Mrs. Kelly's testimony, institutional police immediately do whatever staff tells them. They do not listen to patients and they do not listen to family complaints and that is a very dangerous situation. The State should be required to have a plan for an independent investigative agency that is neutral, that has standard operating procedures like every other police department in the area for investigation of rapes, for investigation of assaults, that requires that the local county hospital be used for testing, for evidence, and for injury just like every other police department would do, for immediate transportation of the victim, for questioning all witnesses, so that they must adhere to that procedure.

That way there will not be two systems of justice, one for patients and one for everyone else, and it will be more uniform.

Senator **Simon**. I thank you.

Senator **Weicker**. Thank you very much. I think the Senator touches upon a good point and I think your answer is a good answer and we will develop this as the hearings progress.

There is a wall of secrecy that by virtue of the law the lack of it is impervious to any independent oversight or investigation. The accreditation procedures themselves are a farce. They are a farce. States are certifying themselves. And the Joint Commission on Accreditation of Hospitals goes through a certain ceremony and then they disappear. There is no oversight or check. That is the problem we are dealing with. I think the Senator brings up a very valuable point and one that will be continued to be developed during the hearings.

I would now like to move on to Maureen Kelly. Maureen, nice to have you before the committee. Why don't you proceed with your testimony.

STATEMENT OF MAUREEN KELLY, TRENTON, NJ

Ms. **Kelly**. Yes. I have a son 27 years old. Two years ago he received severe to moderate brain damage due to a cold sore virus. Unfortunately, he is on Medicaid and I have had problems right from the start trying to find an appropriate placement for him.

He is one of many people, persons male and female, who seem to fall through the cracks. They are not mentally retarded. He was not born that way. He is not over age 65. And no State likes to put its funds outside of the State.

Unfortunately, in addition, the State of New Jersey has no appropriate placement for brain damaged people of the type that Jim has. Now, do not get me wrong; Jim is not unique. He is not the only one. There are loads of people in New Jersey and throughout the United States and the world.

It is a relatively new thing. They need cognitive therapy to reach their potential. Many of them return home apparently well, apparently mentally fine. Others return back to the community and they have deficits but you and I will not notice them. Others have deficits but return to the community and still can function at some kind of a job.

And then there are some that remain in institutions, but God willing, a proper type of institution with people who are trained to know how to deal with them and cope with them.

Psychotropic medications do not help these people. Restraints do not. You just need a proper staff. Let me go on.

Jim has sustained many indignities and abuses since his injury. Even at present Jim finally—finally Medicaid told me after they led me on a wild goose chase to find a place within the State of New Jersey, which ultimately I found out there was none. Medicaid said, yes, there is none, and many other agencies also knew that there was not any.

Well, I did that. I did what I was told, being ignorant. Then I was told to go find out after that work, go find a place outside of New Jersey that accepts funding in that State, and then New Jersey will make a contract with them and New Jersey's funds will go with Jim.

Well, believe me, New Jersey and probably other States as well are most reluctant to put their money out of State. An appropriate place was found just 2 months ago for Jim, and we are still going through the system, the bureaucracy, the ring around the rosy, when I was assured that if and when I did find this appropriate placement things would be expedited.

When Jim was in the acute care hospital immediately after his bout with encephalitis, acute care hospitals do not want people in their hospitals once they are stabilized. So they are quick to get them out. Well, they could not find an appropriate placement for Jim. You know the reason why now. But I will tell you what happens when the time is up in the hospital and you do not come up with an appropriate placement within that timeframe. You are sent to any place that will accept you, inappropriate, just a facility that has a bed, an available bed and wants or needs the money. And then you can be denied any and all rehabilitation not only for then but possibly for the rest of your life.

He was in St. Lawrence Rehab Center and that was very good for a couple of months. They were pleased and I was pleased and Jim was progressing and he progressed until he was no longer appropriate for the facility. He was now realizing things, walking, wandering around, going into other patients' rooms. He became a pest.

It being an inappropriate facility, now they put him up for discharge to find another place, but in the meantime they started medicating him and restraining him and increasing the medications. The medications not only did not work, he became more restless. He became constipated. He was not able to attend therapies.

He had mental and physical things that I could see that I brought to the attention of the staff and the doctor there. And I was told to take him home. That is the answer to everything when anybody is in a pickle like this. If you do not like what we are doing, take him home.

Well, it was so bad and being a nurse I knew what the consequences could be. Also the results of his blood work were out of whack. I called in a neurologist over their head who said, yes, get him off.

Then that just quickened the date that Jim went to another inappropriate facility because now I had dared to not only doubt—they knew I doubted—but I went over their head.

All medications were cut, and the place that Jim was supposed to go from there was in Atlantic City. I had it investigated and it was in a very bad section of Atlantic City at the end of the boardwalk. It was an open facility and definitely geriatric, no young persons. There was somebody in their thirties with spina bifida, and, no, they did not have any cognitive therapy or anything.

I work in a geriatric center and at the time I thought Jim was going to a specialized place in Massachusetts or one in Pennsylvania, which fell through, unfortunately. I asked my place of business to please do me a favor, let him come there for I thought a short amount of time, and I will take him home on my days off. I will keep an eye on him and everything will be well.

It was a mistake. It was an inappropriate facility, which I knew, but on my day off Jim became a bit restless He was constipated. Then he had diarrhea and he was vomiting, and even with all his records and me having told everybody that he was just taken off all medications he was put on thorazine by the doctor.

Now, thorazine is not supposed to be given with brain damage. It could cause seizures; it could cause death. Well, this was done on my day off. When I returned to work on Monday I was told you do not have to work today. Go one on one with your son. Can you take him home? I said no. Well, he has to go to Trenton Psychiatric. He never should have come here first unless you know of someplace else. I did not.

Senator **Weicker**. Why don't you start at the point of the Trenton Psychiatric Hospital. Your testimony is excellent testimony.

Ms. **Kelly**. OK. On a Friday in October I had to take Jim to Piscataway for a very important neurological evaluation that would help place him appropriately. When I returned to Trenton Psychiatric in the evening around 7:40 I was met at the door by a patient. You have to knock to get in.

While I had Jim out that day he was very restless, in and out of the bathroom, and mentioned to me that someone took a knife to me. They said are you going to be good or do you want to die. He said both things. He answered no he did not want to die; yes, he is going to be good. And he was afraid.

The person at the door when I came back said to Jim did you tell your mom about the blood on your pajamas. My son did not seem to know what she was talking about. So I asked what are you talking about. And she said not only 1 day but 3 days, Tuesday, Wednesday, and Thursday, and now this was Friday; not only she but two other patients as well saw blood on Jim's pajamas in the morning and also one male attendant.

Senator **Weicker**. Do you want to stop and have a little drink of water?

Ms. **Kelly**. Yes. OK. I did not put any words into her mouth or later on the other patients' mouths. And they were all very clear that it was blood, red blood, bright red blood. Well, I still realized they were patients and I have access to Jim's chart. When I was in I looked at his chart.

On any of those days there were no entries of any sort. So I asked the attendant on duty did she know anything about this. No. And like most everybody else here said nobody ever knows anything. That is standard. I do not know if they are told to say that or not.

I said where is the nurse; no nurse on duty. This is religious on the 3 to 11 shift. There is no nurse. I said, well, I would like to see the doctor. No, first I said—yes, I said I want to see the doctor. And she called the supervisor, and I guess the supervisor called the doctor and my reply was from both of them that, no, they are both quite tied up, quite busy. But do not worry; they will take care of everything and they will get back to me on Tuesday. Now, Tuesday would be 4 days after this.

I still had time for my brief visit, so I told the attendant I wanted out; I was going to take Jim to a local hospital emergency room. The attendant told me no, I cannot do that. Jim has to stay and I have to leave at 9 o'clock. I said I am going; I am his legal guardian and he is discharged pending placement. Give me something. I will sign anything. I want him checked at the hospital.

No, you cannot. I said call the supervisor. He called the supervisor. The supervisor gave the same message. No. I would have to go at 9 o'clock. Jim stays there. In other words, it could not be done.

I got on the phone and I called the Ewing Police. They told me that they had no jurisdiction. I explained everything, and they felt terrible about it. I said I want you to get me out of here with my son.

They said no, you have to contact the grounds police. Well, I had the attendant contact the supervisor again to contact the grounds police. Well, shortly after that the supervisor arrived on the unit, but did not even give me eye contact, went right into the cubicle. Shortly after that the grounds police came.

They questioned me, and I said I want out of here. They said no. One sergeant said no, you cannot. I said yes I can. I am his legal guardian. He is discharged pending placement. I will sign anything. I am going. This place does not care. I am going. He said no, you cannot, and furthermore, you will leave here come 9 o'clock. It was getting close to 9 o'clock. I kind of flipped out.

I said I am not leaving. I am not going anywhere. I said get me the administrator. The administrator is at home. I said, well, get him at home. It was very quickly that I was told that the administrator and the doctor are on their way. The doctor arrived first, very calm, unlike me; I was a nervous wreck. He said what can I do for you. I said nothing. Just let me out of here. No.

Senator **Weicker**. When they would not let you out of there, you were visiting Jim; am I correct?

Ms. **Kelly**. I had Jim out for the day.

Senator **Weicker**. Right. And you had been told that Jim had blood on his pajamas, right?

Ms. **Kelly**. Right.

Senator **Weicker**. And you had observed the blood yourself?

Ms. **Kelly**. No.

Senator **Weicker**. You had not.

Ms. **Kelly**. No.

Senator **Weicker**. And what led you to believe aside from the statement that somebody made, somebody had said that somebody had taken a knife——

Ms. **Kelly**. My son that day was extremely nervous and in and out of the bathroom. That day I attributed it to he was going for this evaluation, and I did tell him what we were going to do. He does not always remember. I thought maybe it made an impression, and he was nervous. But a combination of in and out of the bathroom—he was not really even able to be evaluated. That is written in his supposed evaluation.

And there was also a statement about a knife, and up to that point I had never heard about a knife. Now I hear it constantly, a knife, but then I had not. And also are you going to be good and do you want to die. And he was afraid. I put two and two together and I thought he had received some kind of abuse.

Senator **Weicker**. You were afraid for your son's life.

Ms. **Kelly**. I thought more in the area of sexual abuse, yes, sir.

Senator **Weicker**. And the final upshot of this, what was the problem?

Ms. **Kelly**. Jim was grossly fecally impacted.

Senator **Weicker**. He had not been able to go to the bathroom?

Ms. **Kelly**. That is right.

Senator **Weicker**. Had this been indicated to you by the staff at the hospital?

Ms. **Kelly**. Definitely not.

Senator **Weicker**. How did you find it out?

Ms. **Kelly**. When the doctor said that I could not leave and take Jim to the general hospital to be examined I asked her for a complete physical examination with specific attention to the rectal area and me be present that Friday night. And she said, yes, that will be fine. So Jim was taken into another room and when he was starting to be disrobed, first the doctor said this is diarrhea, and then when she examined him she said he is impacted.

And she ordered—and I could tell myself that he was. And she ordered a suppository STAT, monitor Jim's bowel movements, feces for blood times three, check his clothing and his bedding and chart any and all.

The next day I arrived—now, this suppository was supposed to be given right away or 5, 10, 15, 20 minutes later, but that evening. I went to work the next day and I arrived at TPH after work around 3:30 to check the results because my son cannot remember and he tends to tell what he thinks you want to hear. So if he thought you wanted him to say he moved his bowels he would say, yes, I did.

No record, no documentation, nobody knew anything. As a matter of fact, the 3 to 11 shift did not even know of the incident the prior evening.

Well, I did get the supervisor; no nurse on duty again. I got the supervisor and——

Ms. Sands. Mrs. Kelly, I have a question. Did not three patients tell you they had seen him bleeding?

Ms. Kelly. I told you that, three patients.

Ms. Sands. Then the police came. Did they interview anybody or did they just—what did they do?

Ms. Kelly. Eventually they interviewed the three patients. I saw them, so they have statements.

Ms. Sands. Did they make you leave before that?

Ms. Kelly. Oh, I was supposed to be gone. No, I was not supposed to be removed specifically for that. I was supposed to be removed by 9 o'clock before anything was being done.

Ms. Sands. Did they interview anyone before they asked you to leave?

Ms. Kelly. Oh, no.

Ms. Sands. Did they interview any of the patients who had said they had seen blood before they asked you to leave the ward?

Ms. Kelly. No. I was still on the ward because now I had permission because the administrator and the doctor were coming. And that is when they were——

Senator Weicker. Is your son still at Trenton Psychiatric Hospital?

Ms. Kelly. Yes. He is still at Trenton Psychiatric. Those stools for blood were never done. I kept telling them at the time they were important to be done and they were not.

Senator Weicker. Has the impaction problem been cleared up?

Ms. Kelly. That one ultimately because I took him home I think it was 4 days later after tussling with TPH. I brought him home. I did a rectal on him myself. It was gross impacted after they told me, no, he was fine. And I gave him two enemas for which in the chart there are a lot of derogatory and intimidating statements about me. And since this incident my brief visits with my son have been greatly curtailed. They have to be okayed not only by the doctor but also by administration. And I feel all I did was what they should have done in the first place. I was following through 3 out of those 4 days and got nowhere. As a mother, I would do it for anybody.

[The prepared statement of Ms. Kelly follows:]

TESTIMONY OF MAUREEN KELLY, R.N.

(PARENT)
TRENTON, NEW JERSEY

HEARING APRIL 1, 1985
SUBCOMMITTEE ON THE HANDICAPPED
WASHINGTON, D.C.

I, Maureen Kelly, a Registered Nurse (licensed by New York and New Jersey), employed at Donnelly Memorial Geriatric Center, have a son, James Kelly, (age 27). I am his legal guardian and have been active in nursing for 30 years.

Jim sustained moderate to sever brain damage - June 1983 - caused by Herpes Virus Type I encephalitis. Presently, Jim is physically fine, but has severe memory losses in specific areas only, and difficulty retaining new memories.

Indignities and abuses Jim has suffered are as follows:

1. Jim is a Medicaid patient and New Jersey has no appropriate placement for persons like Jim. Knowledge of such places are scant to doctors, social workers etc., and Medicaid offers no assistance in finding such places out of state. Medicaid had me and a social worker research placements, to only find out what it knew all along (no place in New Jersey). Then, I had to find a place outside of New Jersey which accepts Medicaid. Doing so, New Jersey refused to fund "Greenery" in Massachusetts - late 1983.

2. Acute care hospitals act expediently and will place persons inappropriately (when accepted) even if it means denying persons any and all rehabilitation. (Middlesex Hospital - August 1983 - Roosevelt Geriatric Center).

3. Short-term rehabilitation centers, when patient progresses to being inappropriate for facility, put patient up for quick discharge, and proceed to restrain and medicate to make the patient appropriate for facility - despite adverse reactions which can be extremely dangerous and possibly life-threatening (St. Lawrence Rehabilitation Center - January to May 1984). Doctor refused to acknowledge and act on my observations even with abnormal lab reports, and physical and mental symptoms present. I had a neurologist enter, and he advised Jim's medications discontinued. During this phase, Jim was unable to actively participate in therapies. Then, patient is discharged to first appropriate facility which accepts them (end of May 1984 - geriatric facility in Atlantic City).

4. Jim, with history of medications discontinued in May 1984 was put on Thorazine (DMH June 2 or 3, 1984) which is contraindicated in brain damage persons, as it can cause seizures.

5. Admitted to Trenton Psychiatric Hospital June 5, 1984, I was promised that Thorazine would be discontinued quickly by the doctor on site. He was aware of the danger. This was not done, despite my pleas to doctors and social workers. Jim had a seizure on June 14th. I was not told till June 21st by a Social Worker. Only a lawyer was instrumental in having Thorazine discontinued.

6. Since admission to Trenton Psychiatric Hospital, most staff are unwilling to answer even trivial inquiries. I'm advised to contact doctors, which is almost impossible and they change every 2 - 3 months. Hence, no follow thru etc.

7. Patients and visitors (other than own) not permitted to converse about anything. It's a rule!! Staff angry and parties scolded and intimidated.

8. After seizure in August 1984, doctor ordered neurological consult. Specialist ordered lab and EEG. I had Trenton Psychiatric Hospital re-order lab as Jim refused it (patient's right). EEG not done to date, despite my numerous pleas. Also neurologist never followed through.

9. Drake Building - sterile atmosphere. Games locked in closet, staff reluctant to supply same when requested. No readings or writing materials openly available. Patients locked behind large doors. They watch T.V., walk, sit, and smoke cigarettes on schedule. Many time, their bedrooms are locked. Jim complains to me "They make me walk nude after my shower until they get me new clothes."

10. They send regular patients to other units just to sleep, when new patients arrive, causing overload. Why do regulars move?

11. Recently, it took me 3 1/2 weeks to get Jim's locker put in with him, after his bedroom was changed, and Jim has memory problems.

12. October 4, 1984, I took Jim home overnight. Jim kept saying: "A guy put a knife to me and said - do you want to die and do you want to be good." Jim's reply was yes to both and he was afraid. I didn't pay any attention really, as Jim makes sense at times only. Returned to Trenton Psychiatric Hospital at 7:40 p.m. Friday, and a patient came to the door when

I knocked for entrance. She asked Jim "did you tell her about blood on your pajamas?" Jim appeared to not know what she was talking about. She went into detail. "Tuesday, Wednesday and Thursday I saw blood - red - like when you have period." She said two other patients also saw blood.

I have access to Jim's chart and found no entries for these days.

No nurse on duty (a regular occurrence on 3 - 11 shift). I questioned one attendant regarding same. She said she knew nothing. I explained my deep concern and asked her to call the supervisor and doctor, as I wanted them to examine Jim right away. Reluctantly, she made a call and informed me that both were very busy, couldn't come, and said it would be investigated and I can check back with them on Tuesday. Then I asked to be let out with Jim, to go to Mercer Hospital E.R. She refused, even though my Brief Visit pass was still in effect. A second attendant arrived. She told me Jim probably has hemorroids - you can't believe what Jim and other patients say. I stated I am Jim's legal guardian, he's discharged pending placement and I'll sign anything, just let us out of here. Attendant stated that I must leave by 9:00 p.m. and without Jim. Time: 8:00 p.m.

I called Ewing Police - not their jurisdiction, and was advised to call Grounds Police. The attendant called the supervisor to inform her that I now wanted the police right away. I asked the attendants for their names. One gave it reluctantly, another willingly. However, a third outrightly, nastily refused even after I explained that the matter hadn't

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to do with him. I just wanted names. He had a name tag on his pants pocket, and as he slowly walked away, I reached for the tag to read the name. He quickly pulled away - tag in my hand now. I read the first name and he quickly snatched card, was verbally angry, read me his rights and my wrong, and said that he would press charges against me. Supervisor arrived at 8:40 p.m. and refused to speak with me. She remained in closed cubicle. Two Grounds Police arrived, entered the cubicle, and spoke with supervisor, then me. I explained all - insisted on being let out with Jim to go to the hospital - stating "legal guardian, discharged, etc., and I'll sign anything." Officer refused to let Jim out, and said I would have to leave at 9:00 p.m. alone. He also stated Jim probably has hemorrhoids. I told him that I would not leave at any time without Jim. He too, told me that Trenton Psychiatric Hospital will check it out and get back to me on Tuesday (4 days hence). I insisted on seeing an administrator. Shortly after this, he informed me that I could stay, and the doctor and administrator were on their way. The doctor arrived and said: "What is your problem - why are you so emotional - your fears are unfounded - Jim probably has hemorrhoids - what can I do for you?" I went through it all again and said: "I want out of here." "Jim can't leave now, you and everyone else were too busy before." She replied: I'm here now, what can I do for you?" The administrator arrived. I insisted on a complete body check with special attention to rectal area, and that I be present. The doctor said "Fine." Jim had undershirt and gown on, and only the rectal area was examined. The doctor said: "He has diarrhea". Rectal exam result showed Jim to be grossly impacted. The doctor ordered a laxative suppository stat, feces for blood x 3, check patients clothing etc. for blood and review on Tuesday. On October 6th at 3:45 p.m., I arrived to check results of suppository etc. No nurse again - no progress notes, doctor's orders not noted and stat suppository not given. Attendant called supervisor for me, who stated she was too busy, and to just wait.

At 5:00 p.m., a nurse arrived to give medications. She was busy and told me let the supervisor handle this matter. Nurse did promise to call the doctor STAT for me, and also re-notify the supervisor.

At 5:35 p.m., I had attendant call supervisor, but another supervisor spoke to me.

At 6:45 p.m., the second supervisor arrived - reviewed all - did rectal exam at my request, which confirmed impaction remained and the first supervisor inserted the suppository.

October 7th, at 3:15 p.m., I arrived to check results of suppository. Chart read "Patient states he moved bowels." No nurse again. I requested to speak with supervisor, and I was escorted upstairs to speak with her and the administrator for a long time. I was informed that I was out of order and distraught on October 5, I have alienated myself from attendants, there is a strong chance that the male attendant who refused to give me his name on October 5, will be reluctant to care for Jim, and that he could press charges against me. Administrator said that she feels a transfer to Med./Surg. Unit would prevent possible lack of care from her staff due to incident.

She told me that any time I want Jim out - the "magic words" are "legal guardian, discharged pending placement." I told her that these "magic words" were used 4 - 5 times October 5th and that she knew it. After talk, supervisor did a rectal at my request and assured me all was well.

October 9 - I arrived to take Jim home - Jim had feces in his pants. Doctor did rectal at my request and said "just soft feces." At home, I gave him an enema and got unbelievably gross amounts of firm stools. I reported same, and very derrogatory statements were entered into progress notes about me, and since then Jim's out visits must be okayed by the doctor and administration, making it very difficult for me to take Jim out. Jim's tests for blood were never done.

13. T.P.H. since Jan. 1985 are denying Jim brief visits with male companion engaged by me to provide him with activity, stimulation and cognite therapy. Since late Feb. they have denied Jim brief visits with me Monday thru Friday. As of March 14, the only scheduled activity Jim attends is on Wednesday for 1hr.

Maureen C. Kelly

P.S. - Since all these indignities and abuses and more have factually happened to my son with me actively involved, I can't help but wonder what does or does not occur to other patients who have no one to champion their cause.

Senator **Weicker**. All right. Maureen, I might have a further question, but let me proceed to the next witness at this time if I might.

The next witness is Jenni Tolska. Jenni, I believe that you are here under subpoena. Would you please stand and raise your right hand.

Do you swear to tell the truth, the whole truth, and nothing but the truth, so help you God?

Ms. **Tolska**. I do.

Senator **Weicker**. Please proceed with your testimony.

STATEMENT OF JENNI TOLSKA, R.N., STATE OF NEW JERSEY DEPARTMENT OF HUMAN SERVICES, BUREAU OF MENTAL HEALTH SERVICES, TRENTON, NJ

Ms. **Tolska**. I am a registered professional nurse working for the division of medical assistance and health services within the department of human services in New Jersey.

At the time the Medicaid program was implemented in 1970 I became a member of the inspection of care team in the bureau of long term care. Since 1981 there was a reduction in force, and I transferred to the present bureau of mental health services and am responsible for the evaluations in the institutions for the mentally ill and mentally retarded. Because I am a registered nurse this report reflects my findings and experiences in reviewing medical and nursing services as well as rehabilitative services provided by other disciplines sharing the same scientific principles and knowledge in our basic education.

The State psychiatric hospitals are administratively a branch of the division of mental health and hospitals under the department of human services. The division does their own licensing surveys with permission of the department of health.

The institutions for the mentally retarded are administratively a branch of the division of mental retardation under the department of human services.

The department of health performs licensing surveys of the certified ICF cottages while the division itself performs licensing surveys in non-ICF cottages. The inspection of care team of the bureau of mental health consists of 14 registered nurses and two nurse supervisors equally distributed for the northern and southern half of the State.

Educationally, the nurses are licensed, have bachelor's degrees and master's or credits towards a master's degree. The nursing staff reviews and interviews 100 percent of all the patients currently present including any discharges that may have occurred over the year.

The team also includes six master's prepared social workers with one supervisor who performs reviews throughout the State on a random sample basis. They review all of the 5 to 13 year olds, since we have one facility just for this age group. And when findings indicate problems they will increase their random sample.

We also discuss client problems with staff for purposes of verification.

The periodic medical review is performed in the psychiatric institutions by the application of the Federal regulations and the legal definition of the nursing practice act and standards of practice which govern nursing practice in our State.

We also utilize standards of practice governing other licensed practitioners and certified disciplines as well as having staff in our central office available for consultation.

Efforts are made to spread our review process over at least a 6-month period, which provides a more individual, indepth report for each ward, cottage, or unit. Many of these reports depend upon the number of cases reviewed in a specific area. Within the last 3 years I have suffered staff turnover and oftentimes find myself in the position of reviewer.

This in turn has enabled me to support my staff and encourge them to identify and criticize the deplorable practices, poor programming, and unsafe environments which we observe. The final yearly annual periodic medical review report is a collection of the smaller reports and does not always include detailed findings. Therefore, the report the Health Care Financing Administration receives may not always indicate severity of conditions.

More recently we are including and identifying these conditions by bringing them to the attention of our director and HCFA region II because corrections are not being made in good basic care.

Findings in psychiatric hospitals: The organization, rules, and regulations in the State psychiatric hospitals clearly delineate the categories and composition of the professional clinical staff, their functions, and responsibilities. The professional clinical staff of the hospital shares responsibility for quality of care. This statement simply means that when mistreatment or wrong doing is observed by anyone in that institution it is as much their responsibility as the person in charge of the guilty staff member.

The services being provided in the psychiatric hospitals reviewed by my staff and myself are below minimally acceptable standards. Reports dated in 1983 and 1984 support this statement. The major deficiencies occur in the activities of daily living, which include eating, bathing, dressing, grooming, toileting, and ambulation, all of the skills of daily activities.

Needs in any of these areas are met primarily by nursing service with concentrated therapy by occupational and physical therapists as required depending on the patient's handicaps. Nursing staff should follow through on these specialty services.

We have observed patients' food trays being removed untouched by the patients and no effort by staff to feed the patients. Extra fluids are not provided. There is no collaboration between medical, nursing, or dietary to resolve dietary problems.

After the 1983 PMR in Trenton Psychiatric Hospital I had a meeting with the nursing supervisors and the assistant director of nurses, and I was appalled because the supervisors informed me that on one particular floor there was never enough food to go around to all the patients, so that meant that usually at one meal there were at least 12 to 15 patients who did not eat at all. This occurred at every mealtime.

Senator **Weicker**. This was where.

Ms. TOLSKA. Trenton Psychiatric. We see extremely obese adolescents whose obesity obviously affects their mental health, and they themselves are requesting special diets, yet they do not receive dietary counseling. Adaptive equipment is lacking, and many times patients who are incontinent are forced to eat their meal in that State.

We have not observed any real individualized toilet training programs. Those patients retaining some stage of continency are not walked to the bathroom unless they are able to do so themselves. In one of the institutions we observed one female with a distended bladder and ignored by staff until we mentioned it, and yet there was no documentation in the chart concerning the problem. We still do not know how that distension was relieved.

Fecal impactions are a daily occurrence, and there is no connection in the institution staff's mind between impactions, diet, fluids, exercise, which are a common method of preventing these. There is no association between diet, fluids, and malnutrition. They do not recognize the signs of malnutrition. There is no relationship between, diet, consumption of food, and weight loss.

They are supposed to take monthly weights, and you can see patients losing as many as 10, 15 pounds, and yet there is no concern about it.

Malnutrition is a common condition in the elderly on the medical wards. Significant weight loss is not treated until the patient is in a malnourished state, and by that time they had a multitude of problems.

Activities are nonexistent. Staff are observed putting puzzles together or playing Scrabble alongside a patient, but there is no interaction between the staff and that patient.

Ambulation programs are lacking; patients are contracted like pretzels, and from experience I know that did not happen overnight. They are sheet-restrained in their chairs all day long and never repositioned or permitted to stretch out on their bed. But we have observed staff lying on a couch in the patients' lounge covered by a sheet and the shoes off taking a nap on their break time, and yet the patients are never allowed to stretch out on their beds.

There is an overuse and misuse of seclusion and restraint in the elderly as well as the adolescence. It is particularly disturbing seeing young people's behavior not properly managed, and the lack of evaluation by a professional to determine whether seclusion or restraint is needed in a given situation.

I just want to refer to Ms. Sands' reading of that portion of her report concerning seclusion and restraint. I was part author of that section.

We never see any notes or documentation concerning aggressive behavior and how it is treated. In 3 short years I have already evaluated the same youngsters moving through the system. First I have seen them in the institution for the 5 to 13 year olds. Then I see them in the Trenton Psychiatric Adolescent Center, and then we also visit a residential treatment center in Pennsylvania on a yearly basis, and I have seen several of the children there.

Even the adolescents are recognizing that they are in the adolescent center too long. Some have been in there 2 years waiting for placements and because a sister agency does not have the proper placement or take the time to find the proper placement, these youngsters are still there, and these are our chronics of tomorrow.

Several months ago in one of the other State institutions one of my staff observed an underaged 22 year old male who has a dual diagnosis. Now, by dual diagnosis we mean he is mentally retarded as well as having a psychiatric diagnosis. He was placed in seclusion without an order in retaliation for aggressive behavior. That day the wind chill factor was below freezing and half the ward was so cold that all the other clients' mattresses had to be dragged to the warm half of the building.

Unfortunately, the seclusion room was in the cold section of the ward. The young man was observed lying on the cold floor without a mattress, blankets, or additional clothing, and the door was locked. The nurse on the floor had apparently interceded in his altercation with another client and had her glasses knocked off. I suggested that my staff nurse call the public advocate's office.

The representative arrived about an hour later and still found him in the seclusion room. But at that time he was told that the door was not locked. I think we referred this to Ms. Sands' department.

Along with this same case, the treatment team allows this young man to go home where he is physically abused by his father, and then of course he returns and he in turn acts out the same behavior.

During our current review we have observed——

Senator **Weicker**. What do you mean he acts out the same behavior?

Ms. **Tolska**. He is ready to abuse others in turn because that is all he knows.

During our current review we have observed only two aides—and this is going back to Trenton Psychiatric—and one R.N. on the late afternoon shift caring for approximately 30 patients. The majority of these clients are very debilitated and require total care. Recently they are phasing out some of the buildings, so they have had to move younger clients into one of the wards with the elderly.

These clients are able to go to the cafeteria on their own, but they must be accompanied by an aide. So when that aide takes them to their evening meal, this leaves one aide and one R.N. with approximately 20 to 22 patients to feed.

Now, it takes at least 15 to 20 minutes to feed someone who is a fast eater. So you figure out the mathematics there yourself when it comes to feeding.

[The prepared statement of Ms. Tolska follows:]

PREPARED STATEMENT OF JENNI TOLSKA

Introduction

I am a registered nurse working for the Division of Medical Assistance and Health Services within the Department of Human Services.

At the time the Medicaid program was implemented in 1970 I became a staff member of the Inspection of Care team in Long Term Care. In November 1981 there was a reduction in force and I transferred to the Bureau of Mental Health Services. My experience in psychiatric nursing was somewhat limited and nil in the care of the mentally retarded. However, my experience in Community Health Nursing and reading and attending inservice educational programs helped me update my knowedge in order to evaluate these groups of people. The experience in long term care helped considerably because the physiological changes occurring in the elderly are a constant and care needs only be adapted to their particular handicaps.

Because I am a registered nurse this report reflects my findings and experiences in reviewing medical and nursing services as well as rehabilitative services provided by other disciplines sharing the same scientific principals and knowledge in our basic education.

Psychiatric Hospitals

The state psychiatric hospitals are administratively a branch of the Division of Mental Health and Hospitals under the Department of Human Services.

The division does their own licensing surveys with permission of the Department of Health. The question of "conflict of interest" arises. Furthermore until about a year ago there was no nurse representation on that team.

Institutions for the Mentally Retarded

The Institutions for the Mentally Retarded are administratively a branch of the Division of Mental Retardation under the Department of Human Services.

The Department of Health performs licensing surveys of the ICF cottages while the division performs licensing surveys in the non-ICF cottages.

Inspection of Care Team

The Inspection of Care team or reviewers for the Bureau of Mental Health consists of fourteen (14) registered nurses and two supervisors equally distributed for the northern and southern half of the state. Educationally the nurses are licensed, have bachelor degrees and masters or credits towards a masters degree.

The nursing staff reviews and interviews one hundred percent (100%) of all the patients currently present including discharges for the year.

The team also includes six masters prepared social workers with one supervisor who performs reviews throughout the state on a random sample basis. They review all of the five to thirteen year olds (we have one facility for this age group) and when findings indicate problems will increase their sample.

Periodic Medical Review

The Periodic Medical Review (PMR) is performed by the application of the Federal Regulations (CFR 42 Public Health 400), the legal definition of the Nursing Practice Act and Standards of Practice which govern nursing practice in my state. We also utilize standards of practice governing other licensed practitioners and certified disciplines as well as having staff in our central office available for consultation.

Efforts are made to spread our review process over at least six months and providing a more individual, in-depth report for each ward, cottage or unit. Many of these reports depend upon the number of cases reviewed in a specific area. I have suffered staff turnover and oftentimes find myself in the position of reviewer. In turn this has enabled me to support my staff and encourage them to identify and criticize the deplorable practices, poor programming and unsafe environment we observe.

The final annual Periodic Medical Review report is a collection of the smaller reports and does not always include detailed findings. Therefore the report the Health Care Financing Administration receives may not indicate severity of conditions. More recently we are including and identifying these conditions by bringing them to the attention of our director and HCFA Region II because corrections are not being made.

Findings in Psychiatric Hospitals

The organization, rules and regulation in the state psychiatric hospitals clearly delineates the categories and composition of the professional clinical staff, their functions and responsibilities. The professional clinical staff of the hospital shares responsibility for quality of care. This statement simply means that when mistreatment or wrong-doing is observed corrective action should be as much the responsibility of the observer as the person in charge of the guilty staff member .

Nursing Responsibilities

Physicians and nurses are held legally responsible for patient care; however, these are the very disciplines consistently found deficient. Probably it is because they are dependent upon one another. Probably because nursing staff is with the patient twenty-four hours a day and cannot walk away as easily as the occupational therapist who provides an on ward therapeutic activity for one hour a day several times a week. Or the physical therapist who provides off ward therapy while nursing staff delivers the patient to the therapist and again returns the patient to the ward. Though patients may attend off ward programs and activities nursing staff must coordinate the plans to ensure patient participation.

There is much overlapping of functions between nursing and other therapies that closer collaboration in planning care would enhance the quality of programming and thus the quality of active treatment for the patient.

When I am asked at PMR's where in the regulations does it state that a registered nurse must attend the treatment plan meetings, I refer them to the state laws governing the activities and practice of nursing for the registered nurse and practical nurseand specific sections of CFR.42.

According to law nurses are responsible for the implementation of the medical regimen which includes the administration of medications and treatments and ensuring that laboratory, diagnostic work or consultations are carried out. Also according to law nurses must implement their nursing plan which includes interventions for managing/meeting aperson's mental, physical, emotional behavioral and social needs and preserve functional needs and ensure a safe environment.

There is a clear line of demarcation or separatism between nursing staff and other professional disciplines. These disciplines participate in the treatment plan meetings, provide their service, directly or indirectly, and walk away . People do not understand the differences between the registered nurse, the practical nurse and duties carried out be resident living or direct care staff. Nursing is being diluted because the employer perceives no functional difference between these three groups of people. Thus, state hospitals are unable to attract and retain better qualified, educated registered nurses interested in providing safe, high quality care. The ones who remain already have sufficient years invested in the system making it difficult to leave and begin elsewhere.

Costs and Nursing Staff

When costs and budgets are examined nursing services usually are the first to suffer due to their greater number. Decisions are usually made by number and not patient need.

Any clinically oriented nurse can tell you the differences in time required to provide proper care to a totally incontinent patient versus one who is on a proper individualized toilet training program versus one who is fully continent but due to unsteady ambulation may require assistance from staff getting to the bathroom whether by wheelchair or walking. A properly supervised staff will meet two or more goals simultaneously in this one procedure. First would be the frequent exercise in walking would prevent loss of muscle tone and its effect on the cardiovascular system, respiratory, gastrointestinal systems and motor function. Secondly urinary function would improve. Thirdly reality orientation would be maintained or improved. Fourth, self esteem would improve. Fifth, caring is shown to make that person feel good about himself. Research has shown that the institutionalized elderly suffer anaclitic depression similar to depression in infants who are deprived of proper maternal care. If a patient's needs aren't met the only recourse left is to withdraw from the world.

We are finding in our current reviews that along with the absence of an RN at the treatment plan meeting that professionals other than nursing are making nursing judgments and writing the interventions .

The absence of a nursing assessment, development of care plans and intervention and related documentation by an RN is another step in the erosion of nursing services in the institutional system which will eventually find its way into the private sector. It will also erode the quality of services.

Nursing services are quietly and effectively down graded and exploited for licensing purposes and perceived as having no value within the system.

When costs and budgets are studied the ratio of physician to patient in these institutions should be examined also.

Resident Living Staff

The key to quality care in psychiatric hospitals and institutions for the mentally retarded is the resident living or aide staff. They are unionized, tightly knit, cohesive group who resists supervision and change if it is not in their best intersts. In order to survive in the system new staff must conform to their way or methods of providing care or programming. They perform in ways expedient to them. It is not that they are not taught or lack the knowledge in performing procedures correctly.Management is keenly aware of these conditions and realize the control of staff. In institutions for the mentally retarded staff refuses to take orders from registered nurses or to learn from them.

Supervision

The civil service system procedures are so cumbersome and weak that it precludes weeding out the incompetents. When administration support is lacking supervisors must weigh the personal costs in going through the disciplinary process.

Another issue compounding the problem of supervision is the system of providing aide staff an upwardly mobile career ladder towards obtaining their RN license. The department provides funds for tuition, adjusts working hours and or provide loans for living purposes. At the completion of this education the person returns immediately to the environment which spawned him/her. They never make the intellectual/emotional transition from aide to professional person and continue to work with their "friends". Having worked in the this closed system the personal strength required to supervise , let alone discipline "friends" is tremendous.

Discharge Oriented Service Plan

In 1984 the Division of Mental Health and Hospitals instituted a new format of the current treatment planning process. It is called the Discharge Oriented Service Plan (DOSP) and emphasizes discharge planning from day of admission..

During the planning stages of this new format the Bureau of Mental Health Services agreed to the incorporation of the previously separate nursing care plan into the DOSP.

The DOSP clearly spells out that patient problems are identified in only three areas of function:physical, mental and social. Nursing needs of the patient in activities of daily living are being placed under social functioning without regard to the basic scientific principals which govern nursing actions. Lack of any or all activities of daily living skills impact upon the patient's social functioning but primarily impact upon the physiological functions and responses effecting all the body systems. It is difficult to determine whether this format emphasizes the deficiencies or whether this organized method enables us to locate and identify them easily.

Findings in care

The services being provided in the psychiatric hospitals reviewed by my staff and myself are below minimally acceptable standards. Reports dated in 1983 and 1984 support this statement.

The major deficiencies occur in the activities of daily living which includes eating, bathing, dressing, grooming, toileting and ambulation. Needs in any of these areas are met primarily by nursing service with concentrated therapy by occupational and physical therapists as required depend-upon the patient's handicaps. Nursing staff should follow through on thsese speciality services.

We have observed patients food trays being removed untouched by the patient and no effort by staff to feed the patient. Fluids are not provided. Theere is no collaboration between medical,nursing or dietery to resolve dietery problems. We see extremely overweight adolescents whose obesity obviously effects their mental health and even requesting special diets yet do not receive dietery counseling. Adaptive equipment is lacking. Incontinent patients are not cleaned up prior to a meal.

We have not observed any real individualized toilet training programs. Those patients retaining some stage of continency are not walked to the bathroom if they are not able to do so themselves. We observed one female with a distended bladder and ignored by staff until we mentioned it and yet there was no documentation concerning that problem. We still do not know what steps were taken to relieve her in either nursing or physician notes.

Fecal impactions are a daily occurence and thereis no connection in staff's mind between impactions, diet, fluids and exercise. There is no association between diet, fluids and malnutrition.

There is no relationship between diet,consumption of food and weight loss.Malnutrition is a common condition in the elderly on the medical wards. Significant weight loss is not treated until the patient is in a malnourished state.

Activities are non existent for the elderly. Staff are observed putting puzzles together or playing games (scrabble) alongside a patient but there is no interaction-between staff and patient.

Ambulation programs are lacking for the elderly. Patients are contracted like pretzels and we know this did not happen overnight. They are sheet restrained in their chairs all day long and never repositioned or permitted to stretch out on their beds. But we have observed staff lying on a couch in the patients lounge, covered by a sheet and shoes off taking a nap at break time.

There is an overuse and misuse of seclusion and restraints in the elderly as well as the adolescents. It is particularly disturbing seeing young people 's behavior not properly managed ; by the lack of evaluation by a professional to determine whether seclusion/restraint is needed in a given situation. No effort is made to distinguish between normal adolescent behavior.

In three short years I have already evaluated the same youngsters moving through the system: first seen in a child treatment center of 5 to 13 year olds; secondly in the state psychiatric adolescent center ; and again in a residential treatment center in a nearby state and sometimes back in the state psychiatric hospital for the adolescents. These adolescents are saying "I have been here too long " but they are dependent upon sister agencies for placement who may drag their feet for many months. These youngsters are well on their way to being the chronics of tomorrow.

Attitudes

One of the major issues in this report is the attitudes of the people invoved in helping this person return to a semblance of functional normal life. Important is the attitude of the professional practitioner providing the care. The attitude of direct care staff who treat patients as inanimate objects. The attitude of administrative staff who provide staff with the time and ongoing knowledge to provide quality care. The attitude of the Medicaid staff who have the fortitude to cite deficiencies regardless of reprisals. The attitude of all to help overcome the sense of hopelessness and helplessness in individuals caught up in a non caring system.

The state agency given the responsibility for monitoring the care negates this trust. The government agency given the responsibility to monitor the state agency is so overwhelmed and impressed with the multitude of forms ,endless forms and guidelines they forget to ask the real questions. There should be at least one person who can fully comprehend statements within the body of a report without a conclusionary summation of inadequate,inferior, incompetent, wretched, deplorable care.

Finally, I wish to go on record that I am not castigating the professional registered nurses but trying to paint a picture of how the system, in its zeal to eliminate the so-called medical

Jenni Tolska, R.N. B.A.

model of health care, is destroying the very essence of nursing services whose primary focus is prevention and wellness.

Jenni Tolska, R.N. B.A.

Senator **Weicker**. Jenni, I wonder if I might go to a few questions I have for you here.

Ms. **Tolska**. Yes.

Senator **Weicker**. I have a copy of the July 25, 1983 periodic medical review report on Trenton Psychiatric Hospital, which I understand you assisted in preparing after visiting the facility with other members of the New Jersey Department of Human Services. I would like to read a few excerpts from the report on the quality of nursing care at the hospital.

> Nursing services were totally noncompliant in the implementation of the medical regimen. There is a total absence of nursing involvement in assessments, evaluation, and planning for the patients' needs. Medications were identified as the most important and only method of nursing intervention, and there is no evidence of active, restorative, rehabilitative nursing measures.

Do these excerpts reflect your findings at Trenton?

Ms. **Tolska**. Yes, they did.

Senator **Weicker**. Now I would like to read the conclusion at the end of the report:

> The magnitude of these deficiencies is such that the level of present treatment falls below minimum standards of care. For this reason significant improvement in the areas of nursing and social services should be undertaken immediately and no later than by early fall of 1983 for the 65 and over age sections of the hospital.

Is that the conclusion you and the other members of the review team prepared?

Ms. **Tolska**. No.

Senator **Weicker**. Your answer is no; is that correct?

Ms. **Tolska**. Right.

Senator **Weicker**. I have here what I believe is an earlier copy of the conclusion which I would like to read:

> A special recommendation is being made by the review team to Mr. Thomas Russo, director of the Division of Medical Assistance and Health Services. If no significant improvement in the areas of nursing and social services is found by early fall 1983 funding should be discontinued for the over 65 section. The magnitude of these deficiencies is such that the level of present treatment falls below the minimum standards of care. For this division to do less would be to sanction negligence.

Who wrote that conclusion?

Ms. **Tolska**. The team did after much careful deliberation.

Senator **Weicker**. In other words, in effect are you stating that the conclusion was altered by your superiors in the division?

Ms. **Tolska**. It would seem so.

Senator **Weicker**. Did they consult with you prior to making that change or give you any reason for doing so?

Ms. **Tolska**. No. We heard about it through our secretary that it was being done.

Senator **Weicker**. Do you have any opinion as to their motive for making those changes?

Ms. **Tolska**. Well, I would like to believe that it was made for the purposes of having sufficient funds to improve care.

Senator **Weicker**. After this report was sent to Trenton were the concerns raised in your report addressed by the fall of 1983?

Ms. **Tolska**. Well, the institution did send their corrections, and the social services did improve, but nursing care did not.

Senator **Weicker**. Now, on June 28, 1984 you and other staff went back to Trenton for the next periodic medical review. I have a copy of the report from that visit here as well and would like to read a few excerpts.

> The problems from last year's periodic medical review have not been corrected and seem to have become more widespread. The R.N. in this institution is seriously jeopardizing her license by not adhering to the standards of practice emanating from the legal definition of nursing practice in this state.

Ms. Tolska. Yes.

Senator Weicker. What did you expect would happen as a result of these two extremely negative assessments?

Ms. Tolska. Well, I would have expected some changes to be made. I know that the nurses on the staff did agree, but they would not talk. They would not talk to me about it. But I would expect that our division should have taken some action.

Senator Weicker. Would you expect that the institution would have been decertified if corrections were not made?

Ms. Tolska. Yes, I would.

Senator Weicker. Were the corrections made?

Ms. Tolska. No.

Senator Weicker. Was the facility decertified?

Ms. Tolska. I am sorry?

Senator Weicker. Was the facility decertified?

Ms. Tolska. No.

Senator Weicker. The Federal monitoring agency for the Medicaid Program is the Health Care Financing Administration. Is it true they regularly receive copies of these periodic medical review reports?

Ms. Tolska. Yes, they do.

Senator Weicker. To your knowledge, have they initiated any monitoring surveys of Trenton to document firsthand the conditions cited in your report?

Ms. Tolska. As far as I know, no. They did come in last fall but just to verify that we were reviewing 100 percent.

Senator Weicker. When was the last time you visited Trenton?

Ms. Tolska. Just very recently, about 2 weeks ago.

Senator Weicker. Were conditions noticeably better than when you wrote those two reports?

Ms. Tolska. My staff nurse and I feel that they are worse.

Senator Weicker. That they are worse?

Ms. Tolska. Yes, if that is possible.

Senator Weicker. Let the record show that other appalling conditions were noted in these reports, including ward activities were totally lacking; patients walked aimlessly or were just sitting; some patients sat in their rooms all day without active programming.

Nonambulatory or debilitated residents are not getting any or very little services. Both the nursing and social service components of the PMR team conferred and agreed that mechanical restraints appeared to be used too frequently, and without the use of alternative methods of behavioral control being thoroughly explored.

By the way, would you tell me what mechanical restraints are?

Ms. Tolska. Well, they use a lot of sheet restraints and there are of certain type of restraints that are made for that purpose. We have seen in one of the other institutions four-point restraints, patients restrained with both wrists and both legs.

Senator **Weicker**. This facility, for the information of the members of the committee, continues to receive Federal Medicaid dollars to the tune of almost $4 million last year.

I also want to say that I think it took a great deal of courage on your part to appear before the committee, very simply put.

Ms. **Tolska**. Thank you.

Senator **Weicker**. I do not know how we are to go ahead and enact binding legislation unless we get first hand knowledge of those who have expertise such as yourself. What I am hoping is that by seeing the visual evidence and the verbal evidence that was heard regarding the abuse of these two children, by listening to someone who is a registered nurse, a highly qualified professional, it will come together in people's minds that this is the shame of a nation.

We should be thankful indeed to have such persons such as Jenni Tolska still in the fight. But, I tell you, you get alarm weary after a time, especially when your superiors are altering reports and nobody gets the word. What do you do?

Is there anything else that you would like to add to your testimony, Ms. Tolska?

Ms. **Tolska**. Not right now. Thank you.

Senator **Weicker**. Is there anything further, Maureen, that you would like to add to your testimony or Carol to yours?

Ms. **Kelly**. I had the chance; you have my full written statement.

Ms. **Sands**. I am just very glad the subcommittee is doing work like this and really trying to find out what the conditions are like because, as it was said before, it is a very secret society not open to the press, and the suffering of these people is a very poignant thing. I have seen it every day for years. I am glad it is being communicated and people are receiving that information because it is not like America in an institution. It is not a democracy. There are not human rights like there are for the rest of us, and it is something that ought not to be like that. It should not be a different place.

Senator **Weicker**. I repeat, how would anyone here like to see this kind of treatment go on in their local medical hospital? How would they like to see their friends and their relatives who are dying of cancer or of heart disease or have arthritis, treated like this?

Ms. **Sands**. In your local hospital if you are not treated right you can leave and go to another one. In this hospital you do not have that choice. As a consumer, even though many of the patients are paying for this care, they cannot leave and go to another hospital. There is no competition. You are stuck there and that is the problem.

Senator **Weicker**. I would also hope that either through the media or by word of mouth, if there are others who have testimony that will bring further light on this subject, the record of this hearing will be kept open for the next couple of weeks, and all one has to do is contact my office here in Washington, DC and they will be put in touch with the committee to get that testimony. I want to make clear that we have had some people are willing to stand up and stand out front on the issue and we will have very dramatic further hearings tomorrow and Wednesday. But I am sure there are a lot of people who have been bottled up for a long time out there who just might want to get it off their chest, and that is fine as far as I am concerned.

The better the record the better the chance that we get this legislation passed. Thank you very much for your testimony.

We will now just break for 5 minutes prior to the next witness.

[Brief recess.]

Senator **Weicker**. The subcommittee will come to order.

I would like to just have a brief elaboration on the remarks I made before we recessed.

If there is anybody desiring to communicate to the committee on the matters pertinent to the committee's jurisdiction, they should contact either Chris Button or Jane West at the U.S. Senate Subcommittee on the Handicapped. The phone number of the subcommittee is (202) 224-6265. Any testimony relative to the subject under discussion here today, tomorrow, and the next day will be gladly received by contacting either Chris Button or Jane West, U.S. Senate Subcommittee on the Handicapped, (202) 224-6265.

I also indicated at the beginning of the hearings that anyone who cared to give testimony on Wednesday in rebuttal of what has been stated here certainly will have the opportunity to do so.

Now, I have to point out as far as the Federal Government is concerned, this is the rebuttal to the testimony that we heard from the Justice Department and others at earlier hearings. It is also fair to say that the various states that might be involved, including my own state of Connecticut, might have additional comment they would like to go ahead and make. And time will be reserved on Wednesday for them. Indeed, if it is not enough time, we will have another day's worth of hearings. But in no way did we attempt to be unfair; I thought it time that voice was given to those behind the walls.

I spent several years hearing from bureaucrats and the people who were not doing anything, and maybe now the time has come to hear from those who should be in our special care. And in no way does this mean to demean any particular agency of the Government or any particular government.

I have to point out that we tried to be even handed in the sense that there will be comments made about the care within my own State of Connecticut. And I do not intend to let this matter rest until it is done right in 50 States including my own.

Now, our next witness is Senator Arthur Ravenel, Jr., of Charleston, SC, and as already indicated by my good friend, Senator Thurmond, it is a pleasure to have you here with us. You have been deeply involved, I know, on these matters in the past and it will be good to hear from you firsthand. Welcome to the committee.

STATEMENT OF ARTHUR RAVENEL, JR., STATE SENATOR, STATE OF SOUTH CAROLINA

Mr. **Ravenel**. Thank you, Senator. This is just like a breath of spring after a long winter to come up here and listen to the remarks you made, your opening remarks to the committee. I really appreciate those remarks. I certainly hope that something substantive will come at the Federal level to the problem that we have all over the country, I am sure.

Prior to January 1983, I did not have any special expertise in the field of mental illness. However, since I am the parent of a 27-year-old Downs syndrome man—and incidentally, Senator, an absolutely marvelous individual. I know you have a mongoloid son yourself. So that makes us members of a very elite and special kind of parentage and the most marvelous experience of my life is being a parent of this terrific human being, IQ 17, social IQ of about 160.

But because of my association in the field of mental retardation I have had some exposure in that area of the handicapped. And in our State we have a separate department of mental retardation, and it is a parallel agency. I would like to happily report to you that down there in South Carolina we have what I would call a good department of mental retardation.

Early in January 1983, an official of the South Carolina Protection and Advocacy Service asked for an emergency meeting with some Senators on the Medical Affairs Committee of which I am a member.

We were told of an ongoing situation at the Blanding Building, which is a unit of the South Carolina Department of Mental Health specifically charged with the treatment of juveniles. Immediately with some staff we drove to this facility and found that what had been alleged was indeed true. Two lady senators happened to be available at the time and they went with me. And a person from the P and A made this allegation, and I said when did this happen. And they said, "Senator, it did not happen; it is going on right now." So we immediately went over there. It is in the city of Columbia, which is our State capital.

Youths ranging in age from 12 to 16 years old had been stripped naked, strapped face down in four-point restraints to the floor, and some had been heavily drugged to lessen their struggles and mute their cries. Though at first denied, it was presently determined that such treatment was the result of suggested guidelines posted on the bulletin board. And I have brought copies of the guidelines, exhibits 1 and 2.

Naturally, the foregoing experience enraged the senators involved, and considerable press was generated over the affair. Publicity caused an outpouring of complaints against the South Carolina Department of Mental Health from various groups including citizens, patients, and personnel within the department. Dozens of inside personnel stepped forward to give testimony.

And just to give you an instance of a typical type situation that we heard, the kind of testimony that came forward, one afternoon after 5 o'clock after they knocked off, I was taking some affidavits from three middle management people. One was a nutritionist. One was a physical therapist. One was a psychologist, all well educated ladies, I would say probably 35 to 45 years old.

I had a staff lawyer there taking the affidavits. Of course I was able to guarantee them immunity from any problems they might have with the department. I started off the interview like this. I said, well, ladies, what is the biggest problem that you are encountering over there? Now, they work in the geriatric unit of the mental health department.

And they said, "Senator, it is the water." And I was completely taken in. I said, the water, what is the matter with the water? And they said, "Senator, nothing is the matter with the water. You have to understand. They do not give these poor old people enough water to satisfy their thirst."

I said, my God, why don't they give them enough water? They said, "well, Senator, you have to understand; if they give them all the liquids they require, they urinate more frequently and you have to change the diapers more often and it makes more work for the staff." That is typical of the type of thing that was and perhaps still is going on down there.

One day I was told by some true friends of the mentally ill of the existence of the Federal Institutionalized Persons Act. And they suggested that perhaps I might try to involve the Justice Department via this statute.

Late in March of 1983 I called upon Mr. Henry McMaster. He is the U.S. attorney for South Carolina and I asked him to help me involve the Federal Government. On March 30 I wrote McMaster my concerns and requests, and by letter of April 16 he requested of Mr. Paul Lawrence of the Justice Department that a preliminary investigation under the terms of the act be initiated. And I have brought the exhibits. They are 3 and 4.

Shortly thereafter I was contacted by telephone by Mr. Charles Sneider of Justice. He was generally supportive of our cause, but he cautioned me against expecting quick action and cited problems Justice had experienced previously in trying to involve itself under title 42, section 1997 of the U.S. Code.

There followed months of frustrating phone calls and correspondence with the Justice Department by both me and the U.S. Attorney. The U.S. attorney down there really hung in there with us. Literally reams of material to support our plea was forwarded to Washington. Finally 6 months later, on October 6, 1983, Mr. W. Bradford Reynolds, Assistant Attorney General of the Civil Rights Division, wrote the South Carolina Governor that Justice would investigate "conditions at South Carolina State Hospital." And that is my exhibit No. 5, a copy of the letter.

Senator **Weicker**. Six months after you saw these people in four-point restraints?

Mr. **Ravenel**. No, sir, almost 8 months.

Senator **Weicker**. Eight months.

Mr. **Ravenel**. Yes, sir. But they did not get the letter from our U.S. attorney in response to my letter to the attorney. He wrote them on the 16th and they wrote the Governor on October 16 under the terms of the act.

Now, on November 18, 1983 the South Carolina Legislative Audit Council, which is an investigative arm of our general assembly, issued a management audit report on the South Carolina Department of Mental Health. I will furnish you a copy.

Never before has such a terrible indictment been made of a department of the State of South Carolina. I pray that never again will such a disgrace occur; 138 pages of every kind of abuse against the mentally retarded that you could imagine all laid out and documented, 138 pages which you have that literally burn, page after page after page. The tales were written by patients, written by staff, written by people coming in off the street, patient abuse, every conceivable type of patient abuse, trafficking in drugs inside the institution, selling liquor inside the institution, misappropriation and application of funds; you name it, Senator, you have it right there in your hands.

For months after Reynolds' letter to our Governor nothing substantive occurred. On February 15, 1984 I wrote my concerns to Mr. Reynolds, exhibit 6. Among other things I informed him—and I am going to report just a few things from my letter. The investigation lacks zeal. The investigators are inexperienced, and I have enclosed a quote from people inside the department who supported what we are doing down there.

The investigators are inexperienced: "do not know what they are looking for" and are relativeley recent employees of the Justice Department with no or very little experience in the work they are supposed to be doing. That is what I was told by people that they had interviewed.

The investigation—and this is the thing that has really teed me off—the investigation is being limited to conditions in the State hospital. Please be informed that the State hospital comprises only a small portion of the facilities operated by the South Carolina Mental Health Commission. And the investigation needs to be immediately expanded.

No one from the Justice Department has contacted me, and I possess most of the source material which triggered the investigation.

On February 17 Mr. Reynolds told a Columbia newspaper, the statewide paper down there, among other things, that, "I would hope for his sake—talking about me now—that the letter was not made under oath." Exhibit 7. What a charming person and great friend of the handicapped this Mr. Reynolds must be.

Finally, at long last and after many more thousands of written words and numerous telephone calls including the offices of my Congressman Thomas Hartnett and Senator Thurmond. On one occasion I was trying to get through to Justice. They would not return my phone call. I called our big stick, Senator Thurmond. In about 10 minutes the woman called me very apologetically.

And, Senator, the Justice Department on November 23, 1984 issued its report on its investigation of the State hospital, and I have given you a copy of that. The report confirms essentially the findings of the Legislative Audit Council and the suspicions of those of us knowledgeable in South Carolina.

Though limited in its scope, its threat of Federal injunction has spurred the Department of Mental Health to effect improvements, Exhibit 9, and has encouraged the Ways and Means Committee of the South Carolina House to come up with necessary funding. We are in our budgetary process right now, and the house is now debating the appropriation bill, but they have put in all the money that the Department of Mental Health has requested as a result of being under threat of Federal injunction.

From April 16, 1983 until November 23, 1984 is approximately 19 months. It seems to me that this is an outrageous amount of time consumed in finally responding to the desperate plight of a substantial number of handicapped citizens.

I respectfully suggest that this committee take prompt action to right the wrongs in this area which have been made apparent by the footdragging of the responsible division of the Justice Department.

And I would suggest this, Senator, that you take a look at this type of curative legislation; you ought to eliminate from the Institutionalized Persons Act this process where you have to go through the Governor, that you first have to inform the Governor that you are going to come in. All this does when the Governor gets the word is that everybody gets the word, and when everybody gets the word, that is when the coverups start in the Department of Mental Health. They sanitize everything before the initial task force from the Justice Department gets there. And I think you ought to remove that. They ought to be able to go right on in there.

You are federally funding them; it is Federal tax bucks that is putting that money in there, and, by George, you ought to be able and I think you are able to go right on in there.

Then I think you ought to mandate that the Justice Department form a special section to deal with these type of cases, and they ought to form some strike forces to go in initially. You do not have to send 15 or 20 people down there, but if you had some highly skilled individuals, one, two, or three, with some limited staff so that when you get the call you could immediately go on in there, arrive at the door, show your identification, and go right on in there and take a look around.

I think that you ought to give more clout, more money, if it is possible, for these protection and advocacy services which you have created. I mean, you are the genesis of the P and A in South Carolina and I would imagine that they function nationwide. You ought to beef them up. I know South Carolina, whatever they request, we give them; we kick in our share and they do not have any hassle about it either. You ought to beef them up, and I think that they ought to be able to trigger an investigation.

If after they have looked into a situation, I think that if the protection and advocacy service calls for a strike force from the Justice Department to come in under the Institutionalized Persons Act, by George, they ought to be able to respond to that and not have to fiddle around and fiddle around and have to handle the thing politically and tear their hair and go to the press and everything else. They ought to be able to just go on in there and find out whether the allegations are true or not. Then if they are, you see, then they can bring in a full team to do a complete evaluation and investigation of the institution, and if necessary, put them under injunction. Thank you, sir.

Senator WEICKER. Senator, thank you very much. I have one question here. I might add, it is extraordinarily helpful to have somebody at the State level of government to put the rest of the pieces of the puzzle together here. Your testimony speaks very eloquently to the problem.

On April 16, 1983 the U.S. Attorney for South Carolina appealed to the U.S. Department of Justice to begin an investigation of "serious allegations of systematic abuse of patients confined to the South Carolina Department of Mental Health."

He requested that the Civil Rights Division "commence an investigation immediately." Yet it took the U.S. Department of Justice 6 months to respond to this request and 13 more months to issue the findings of their investigation. Did anyone ever explain to you, Senator, why this investigation took so long?

Mr. RAVENEL. Well, I had extensive conversations on the telephone with officials in the Justice Department. They told me that they had jumped the gun, as they put it, and I think they said—do not hold me to this now, but I believe this is so and you can check it out. I think they said in the case of Hawaii they went in there precipitously after the act was passed. It might have been some other State, but they can tell you what it was. And they did not cross all the T's and dot all the I's, and they got thrown out and they were severely embarrassed. So they said as a result of that initial involvement, which resulted in an embarrassment to the Department, they were going to be extremely careful about tackling another situation. That is what they told me.

Senator WEICKER. That would correspond to Mr. Reynolds' response to me in the committee back in November of 1983. Again I would have to ask anyone on the committee or anyone listening to these hearings if this were your child, if this were your mother or father, your sister or brother, would you wait 19 months before they are free from death or rape or being in a four-point restraint or walking nude or shut into a room, these first class citizens who have committed no act against society but that of birth or that of illness?

Mr. RAVENEL. The situation there, while the investigation was in progress, the situation where a mentally retarded person 33 years old was sent there by the Department of Mental Retardation to have dosages of dilantin regulated right before Christmas. I know exactly what occured there. The child was put in restraints for 13 hours, naked, died in restraints, rubbed raw by the straitjacket from the ankles, the neck, the wrists, finally taken out, found that she was apparently raped in restraints either before or after death.

I tried everything I could do to get the Justice to come in on the criminal side absolutely to no avail. The solicitor down there who hates me with a passion for pushing him to the wall as hard as I can has thrown in the towel on the investigation. Our SLED, State Law Enforcement Division has done all they can do on the investigation. I have been trying to get the FBI to come and run this thing to the ground because apparently the man or men who raped her in the restraints are still working there at the Department of Mental Health. All to no avail.

I would like to additionally say that this particular case—I do not like to mention the name; it is one of my constituents, a daughter of elderly parents, has been fully documented, marvelous investigative article done by the Charlotte Observer and of course is available to your committee.

We furnished it to the criminal side of the Justice Department. I do not know if you have seen that or not. But, certainly, Senator, you should just take 15 minutes to read it, just the type of things that go on in this country.

Senator WEICKER. It is felt that the perpetrator of that deed might still be working within that department?

Mr. RAVENEL. Yes, sir. And it would seem to me—and I have said it repeatedly. I have said it to SLED. I have said it on the floor of the Senate down there, and I say it to you and I just say it to everybody. I just feel like skilled FBI investigators could come in there and pick up the threads of that investigation and get somebody from Wala Wala, Washington or someplace else who is interested in furthering his career and not into the political implications of who might be involved, a kin of this good old boy or that good old boy. Politics is our national pastime down there.

They could absolutely pick up the threads of that investigation and run it to ground, but so far we have been unsuccessful. If you can help us, help us.

Senator WEICKER. Well, I know that you have helped many people by appearing here today, and I thank you very much for your testimony.

Mr. RAVENEL. Thank you, Senator.

Senator WEICKER. Thank you.

[The prepared statement and additional material submitted by Mr. Ravenel follow:]

ARTHUR RAVENEL, JR.
SENATOR, CHARLESTON COUNTY
SENATORIAL DISTRICT NO. 44

HOME ADDRESS:
[illegible] CENTER STREET
MOUNT PLEASANT, S.C. [illegible]

THE SENATE OF SOUTH CAROLINA

COMMITTEES:
EDUCATION
FISH, GAME AND FORESTRY
GENERAL
JUDICIARY
MEDICAL AFFAIRS

SENATE ADDRESS:
SUITE [illegible]
GRESSETTE SENATE OFFICE BLDG.
COLUMBIA, S.C. [illegible]
PHONE: [illegible]

I am Arthur Ravenel, Jr. of Charleston, South Carolina representing District #44 in the Senate of my state. In the 1950's I served several terms in our House of Representatives. Prior to January 1983, I had no special expertise in the field of mental illness, however, since I am the parent of a 27 year old Down's Syndrome man, I have had considerable exposure to that area of the handicapped.

Early in January of 1983, an official of the South Carolina Protection and Advocacy Service asked for an emergency meeting with some Senators on the Medicial Affairs Committee of which I am a member. We were told of an ongoing situation at the Blanding Building which is a unit of the South Carolina Department of Mental Health specifically charged with the treatment of juveniles. Immediately, with some staff, we drove to this facility and found that what had been alleged was indeed true. Youths ranging in age from 12 to 16 years old had been stripped naked, strapped face down in four point restraints to the floor and some heavily drugged to lessen their struggles and mute their cries. Tho at first denied, it was presently determined that such treatment was a result of suggested guidelines posted on the bulletin board. (see exhibit 1 and 2)

Naturally the foregoing experience outraged the Senators involved and considerable press was generated over the affair. Publicity caused an outpouring of complaints against the South Carolina Department of Mental Health from various including citizens, patients and personnel within the Department. Then one day I was told by true friends of the mentally ill of the existence of the Federal Institutionalized Persons Act and they suggested that perhaps I might try to involve the Justice Department via this statute.

Late in March 1983, I called upon Mr. Henry McMaster, the U.S. Attorney for South Carolina, and asked him to help me involve the Federal Government. On March 30, I wrote McMaster my concerns and requests and by letter of April 16 he requested of Mr. Paul Lawrence of the Justice Department that a preliminary investigation under the terms of the Act be initiated. (exhibits 3 and 4) Shortly thereafter I was contacted by telephone by Mr. Charles Sneider of Justice. He was generally supportive of our cause but cautioned me against expecting quick action and cited problems Justice had experienced previously in trying to involve itself under Title 42, Section 1997 of the U.S. Code. There followed months of frustrating phone calls and correspondence with the Justice Department by both me and the U.S. Attorney. Literally reams of material to support our plea was forwarded to Washington. Finally, six months later, on October 6, 1983, Mr. W. Bradford Reynolds, Assistant Attorney General of the Civil Rights Division, wrote the South Carolina Governor that Justice would investigate "conditions at South Carolina State Hospital". (exhibit 5)

On November 18, 1983, the South Carolina Legislative Audit Council, an investigative arm of the South Carolina General Assembly, issued a management audit report on the South Carolina Department of Mental Health. (copy furnished) Never before has such a terrible indictment been made of a department of the State of South Carolina. I pray that never again will such a disgrace occur.

For months after Reynold's letter to our Governor nothing substantive occured. On February 15, 1984, I wrote my concerns to Mr. Reynolds. (exhibit 6) Among other things I informed him that:

> The investigation lacks zeal.
>
> The investigators are inexperienced, "do not know what they are looking for", and are relatively recent employees of the Justice Department with no or very

> little experience in the work they are supposed to be doing.
>
> The investigation is being limited to conditions in State Hospital. Please be informed that State Hospital comprises only a small portion of the facilities operated by the South Carolina Mental Health Commission and the investigation needs to be immediately expanded.
>
> No one from the Justice Department has contacted me and I possess most of the source material which triggered the investigation.

On February 17, Reynolds told a Columbia newspaper among other things that "I would hope for his sake it (the letter) wasn't made under oath". (exhibit 7) What a charming person and great friend of the handicapped this Mr. Reynolds must be.

Finally, at long last, and after many more thousands of written words and numerous telephone calls including the good offices of my Congressman Thomas Hartnett, and Senator Thurmond, the Justice Department on November 23, 1984, issued its report on its investigation of the State Hospital. (exhibit 8) The report confirms essentially the findings of the Legislative Audit Council and the suspicions of those knowledgeable in South Carolina. Tho limited in its scope its threat of Federal injunction has spurred the Department of Mental Health to effect improvements (exhibit 9) and has encouraged the Ways and Means Committee of the South Carolina House to come up with necessary funding.

From April 16, 1983, to November 23, 1984, is approximately 19 months. It seems to me that this is an outrageous amount of time consumed in finally responding to the desperate plight of a substantial number of handicapped citizens. I respectfully suggest that this Committee take prompt action to right the wrongs in this area which have been made apparent by the foot dragging of the responsible division of the Justice Department.

April 1, 1985

Exhibit 7

USE OF RESTRAINTS IN BLANDING

1. Place patient in prone position (on his stomach) and apply restraints to all 4 extremities, sufficiently secure that they cannot be removed by the patient.
2. Make sure patient is placed on sheepskin to prevent bed-sores.
3. Every 15 minutes loosen each restraint in turn, one at the time only, to permit adequate circulation and exercise of the extremity, than replace securely.
4. Offer fluids via straw to patient every two hours.
5. Offer urinal to patient every two hours.
6. If patient needs to have bowel movement, notify Security to assist by hand-cuffing patient and permitting him to sit on bed-pan. If he does not have a bowel movement, document that he is using the stated need as an excuse to get out of restraints.
7. Offer patient food at each meal; he is to be fed by nursing personnel.
8. Patient is to be given a bath in bed every morning.
9. Depending on the room temperature and on patient's temperature, patient may be covered with a sheet or with a security blanket.
10. Wipe off any excessive sweat possible.

MCB:tcm
T: 12/20/82

(EDITOR'S NOTE: Due to printing limitations and in the interest of economy, a management and performance review by the Legislative Audit Council of the South Carolina General Assembly and exhibits 5 and 7 submitted by Mr. Ravenel were retained in the files of the Committee where they may be researched upon request.)

DMH: Unit OA
Complaints

Exhibit 2

When a student from the Department of Youth Services becomes a patient at South Carolina State Hospital, his management may be most effectively facilitat by initiation of one or more of the following:

SUGGESTED GUIDELINES

1. All patients will remain on the ward with meals to be eaten on ward. Patien must be placed in separate areas.
2. If phone calls and visitors are restricted (suggested 1x/wk.), documentation of this must be on the treatment plan and progress note. The basis for this procedure is their demonstrated inability to handle these responsibilities in the past.
3. Any adolescent admitted to the SCSH from DYS will be admitted to Blanding.
4. On the first day, the patient's counselor will explain the rules and the Behavioral Dictionary, except as below:
5. If he fails to follow the rules just once, he will be placed in time-out.
6. If he fails to go to time-out voluntarily, or fights the staff, he will be placed in seclusion.
7. If he attempts to hurt himself or to destroy the seclusion room just once, he will be placed in restraints.
8. Any time the patient leaves the ward, he will be escorted by Security.
9. Whenever there are 2 or more DYS students in Blanding, access to and from Blanding will only be through main front door.
10. Consideration should be given to nighttime sedation to make certain patient sleeps through the night. This will prevent escape attempts. To avoid possible addiction, sedation should alternate between sodium amytal, chloral hydrate, and paraldehyde.
11. Consideration should be given to vitamin supplementation.

WEM:tcm
T: 12/28/82

SCP&A
RECEIVED
DEC 29 1982
NO: 743
FILE: adm [illegible]
REFERRED: [illegible]

[illegible]
cc: R. O'A

Exhibit 3

ARTHUR RAVENEL, JR.
SENATOR, CHARLESTON AND GEORGETOWN COUNTIES
SENATORIAL DISTRICT NO. 16
OFFICE NO. 4

HOME ADDRESS:
[illegible] EAST BAY
CHARLESTON, S. C. [illegible]

THE SENATE OF SOUTH CAROLINA

COMMITTEES:
AGRICULTURE AND NATURAL RESOURCES
FISH, GAME AND FORESTRY
MEDICAL AFFAIRS
TRANSPORTATION

SENATE ADDRESS:
SUITE [illegible], GRESSETTE SENATE OFFICE BLDG
COLUMBIA, S. C. [illegible]
PHONE: [illegible]

March 30, 1983

Henry D. McMaster
United States District Attorney
1000 Security Federal Building
Columbia, South Carolina 29201

Dear Mr. McMaster:

I have recently been approached by several employees of the South Carolina Department of Mental Health who have expressed serious concerns about that agency and specifically about the administration's response to allegations of client abuse and staff attitudes.

The most disturbing allegation concerns the administration's total failure to respond in any way to approximately 35 client abuse complaints which have been internally investigated over the past 3 years and have been recommended to the administration to be referred to the Richland County solicitor for grand jury action.

These complaints are all currently in the hands of the Legislative Audit Council, which has been conducting an audit of the Department of Mental Health on the request of Senator Tom Smith and Representative Joyce Hearn since January of 1981. Although these documents have been in the possession of the Legislative Audit Council for quite some time now, no referral has been made to our Attorney General's office, as would be expected if any criminal conduct is implicated in the complaints. I am convinced that no action will be taken by any branch of our government, although the complaints allege serious incidents of criminal abuse of patients by both other patients and staff. As examples of these instances of abuse, I have been told of staff members who have left doors open on locked wards in order to hear personal phone calls. As a result of this one patient wandered out of the ward, choked on something while on another ward and was not assisted by the staff of the other ward as he/she was not one of their charges. This patient died as a result of this inattention.

In another case, the staff encouraged a fight between two patients and allowed other patients to encourage them. As a result of this, both patients involved in the fight were injured and required medical treatment.

Mr. McMaster
March 30, 1983
Page two

Although I am not an expert on mental health, nor is that an area of peculiar interest to me, I am the parent of a Down's Syndrome man and have long been involved in and concerned with the practices and conditions in our mental retardation residential facilities. Therefore, when these employees came to me with their stories, I was immediately sympathetic and greatly disturbed by the situation as they depicted it. Ironically, I had also been contacted a short time before by the South Carolina Protection and Advocacy System about a set of guidelines in use at the Children and Adolescent Unit at the State Hospital which they felt, and I agreed, were punitive to the point of being abusive. I've enclosed a copy of those guidelines.

These guidelines were so repugnant to me and to two other Senators that we immediately went over to the Children and Adolescent Unit to observe the treatment of these juveniles. While there I observed a child heavily drugged, lying naked on a bare plastic mattress, covered with a suicide blanket. The guidelines in question were posted and the staff indicated that they were being followed. However an administration official told us they were not approved and were not being followed. I am aware that a lawsuit on behalf of a number of children who were at this unit has been since filed in the Federal District Court, an investigation is being conducted by the Governor's office and also that the Director of the Children and Adolescent Unit is no longer employed by the Department, but I believe that these types of practices and widespread attitudes permeate the entire Department. Furthermore, I am convinced that all the state investigations in the world would come to naught without the objective hand of the Justice Department guiding them. Recently I spoke with a concerned official of the Department of Mental Health about the situation there and I asked him this question:

> "If I were a citizen of meager means, who became mentally ill and who had to seek treatment at our state mental hospital, what would be my chances of being properly diagnosed, treated, and eventually returned to health?"

I was shocked at the answer, which was

> "You'd have no chance at all."

I have heard story after story of abuse which has already been investigated and confirmed within the Department itself and yet not one move has been made by the administration at Mental Health, the Legislative Audit Council, or the Attorney General's office to take action against the abusers. The employees who have relayed this information to me are fearful of reprisal by the Department and are most reluctant to make themselves known. However the Legislative Audit Council has confirmed to me that they have these complaints and will turn them over to the Justice Department should an investigation be initiated under the Institutionalized Person's Act.

Mr. McMaster
March 30, 1983
Page three

The sheer number of complaints -- 300 over a 3 year period -- indicate to me that there must be many more unreported incidences of abuse. These abusers are continuing these outrageous and abominable practices because they know nothing will happen to them. From what has been reported to me and what I myself have seen, I feel that our mental health facility is simply a warehouse for our mentally ill citizens in South Carolina. Through neglect and mismanagement it is being run more like a penal institution than therapuetic and completely lacking in compassion.

It is for these reasons that I am requesting, on behalf of the citizens of South Carolina, the United States Department of Justice to initiate an investigation under the auspices of the Institutionalized Person's Act.

Very truly yours,

Arthur Ravenel Jr

Arthur Ravenel, Jr.

AR/edw

U.S. Department of Justice

United States Attorney
District of South Carolina

Exhibit 4

1100 Laurel Street
Post Office Box 2266
Columbia, South Carolina 29202
803/765-5483
FTS/677-5483

Field Offices

Federal Building, Room 213
300 E. Washington Street
Post Office Box 10067
Greenville, S.C. 29603
803/232-3646 FTS/677-0326

Post Office Building, Room 300
83 Broad Street
Post Office Box 973
Charleston, South Carolina 29402
803/724-4381 FTS/677-4381

April 16, 1983

Mr. Paul Lawrence, Deputy Chief
Special Litigation Section
Civil Rights Division
U. S. Department of Justice
Washington, D. C. 20530

Dear Mr. Lawrence:

Enclosed is a letter dated March 30, 1983, written to me by South Carolina State Senator Arthur Ravenel concerning serious allegations of systematic abuse of patients confined to the South Carolina Department of Mental Health.

Senator Ravenel has asked that these matters be investigated under the Institutionalized Persons Act, Title 42, United States Code, Section 1997, et seq. I agree wholeheartedly that an investigation is warranted and ask that the Civil Rights Division, in whose special authority such matters fall, commence an investigation immediately.

I have enclosed copies of materials provided by the Senator. Senator Ravenel informs me that the Governor's Office, whose investigation of the Mental Health Department is discussed in several of the newspaper articles enclosed, would make those files available to the Department of Justice.

In addition, you may want to discuss these matters at some point with Ms. Margaret O'Shea, an award winning journalist and author of several of the articles, who could save all of us a lot of time. I believe she is thoroughly familiar with the many developments of this matter.

Mr. Paul Lawrence
April 16, 1983
Page Two

I am convinced that the best course for us to take at this time is to proceed with a preliminary federal investigation, despite the presence of other inquiries or investigations and despite the presence of a civil lawsuit which was filed in February, as is described in several of the attached articles. After we collect some preliminary information, we can make an informed decision about what should be done.

I look forward to hearing from you and assisting you in any way.

Very truly yours,

Henry D. McMaster
HENRY DARGAN McMASTER
United States Attorney

RCJ,jr/gda

cc: Senator Arthur Ravenel

- Exhibit 6 -

ARTHUR RAVENEL, JR.
SENATOR, CHARLESTON AND GEORGETOWN COUNTIES
SENATORIAL DISTRICT NO. [illegible]
OFFICE NO. [illegible]

HOME ADDRESS:
[illegible] EAST BAY
CHARLESTON, S. C. [illegible]

THE SENATE OF SOUTH CAROLINA

COMMITTEES:
AGRICULTURE AND NATURAL RESOURCES
FISH, GAME AND FORESTRY
MEDICAL AFFAIRS
TRANSPORTATION

SENATE ADDRESS:
SUITE [illegible], GRESSETTE SENATE OFFICE BLDG.
COLUMBIA, S. C. [illegible]
PHONE: [illegible]

Febraury 15, 1984

Honorable William Bradford Reynolds
Assistant Attorney General
Civil Rights Division
U.S. Department of Justice
Washington, D.C. 20530

Dear Mr. Reynolds:

Several months ago your division announced that it was going to commence a civil investigation into reports of civil rights violations at the State Hospital here in Columbia, South Carolina. I instigated this investigation via a visit to Mr. Henry McMaster, U.S. Attorney for South Carolina. To date I have been informed by various that:

> The investigation lacks zeal.
>
> The investigators are inexperienced, "do not know what they are looking for", and are relatively recent employees of the Justice Department with no or very little experience in the work they are supposed to be doing.
>
> The investigation is being limited to conditions in State Hospital. Please be informed that State Hospital comprises only a small portion of the facilities operated by the South Carolina Mental Health Commission and the investigation needs to be immediately expanded.
>
> No one from the Justice Department has contacted me and I possess most of the source material which triggered the investigation.

The situation down here is as follows: We have a Commission of Mental Health whose administration has become old and out of touch with reality. It has lost both its' direction and purpose to the detriment of the mentally ill of this state and their families and friends. A recent management audit by our Legislative Audit Council has revealed and documented case after case of patient abuse, unexplained deaths, rapes of patients by staff and others, drug trafficing, fiscal mismanagement, and more. Investigative stories by local papers almost daily tell of horror after horror. Despite all this, because of the political influence of Dr. William S. Hall, the Commissioner, nothing of a positive remedial nature is ever done by responsible state officials and agencies. Because of the foregoing, I sought the help of the U.S. Government which, tho announced, appears to be embarrassingly feeble.

Please look into the above and get some knowledgeable people worth their salt down here.

Very truly yours,

Arthur Ravenel, Jr.

AR/edw

cc: Senator Strom Thurmond
Congressman Floyd Spence
Congressman Carol Campbell
Congressman Thomas Hartnett
Senator Thomas E. Smith, Jr.
Mr. Henry McMaster
Mr. Edwin Meese
Mr. Lee Atwater

Civil Rights Division

Office of the Assistant Attorney General
Washington, D.C. 20530

Exhibit 8

ECEIVED
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State Commissioner of
Mental Health
S. C. Dept. of Mental Health

FEDERAL EXPRESS

23 NOV 1984

Honorable Richard C. Riley
Governor
State of South Carolina
P.O. Box 11450
Columbia, S.C. 29211

Confidential

Re: South Carolina State Hospital,
Columbia, South Carolina

Dear Governor Riley:

On October 6, 1983, pursuant to the Civil Rights of Institutionalized Persons Act (CRIPA), 42 U.S.C. §1997, we wrote you to let you know of our intention to investigate conditions at South Carolina State Hospital (SCSH). We met shortly thereafter with representatives of your office, the Department of Mental Health, the Mental Health Commission, and the State Attorney General's office, to discuss the parameters of our investigation. Our activities since that time have consisted of 7 days of tours of the facility by our attorneys, an institutional psychiatrist, and a psychopharmacologist. During those tours, many hospital staff were interviewed and voluminous records and documents reviewed. Additional materials were forwarded to us by the Department of Mental Health, including Board of Inquiry reports which, pursuant to an order of the United States District Court, will be kept confidential by the Department of Justice.

Throughout the investigation, the Department of Mental Health and state officials exhibited the professionalism and cooperation which I believe form the foundation of the joint Federal and state effort envisioned by CRIPA. For the most part, hospital staff also appeared highly concerned with the well-being of the patients entrusted to their care, and I wish to emphasize that our findings should not be construed as an indictment of these persons' good faith or dedication.

We recognize that the deficiencies we have noted may be attributable, in part, to factors beyond the immediate control of the hospital staff, such as institutional funding, recruitment, or past organizational difficulties. Nevertheless, our charge under CRIPA requires that when patterns or practices at a state institution subject persons residing therein to egregious and flagrantly unconstitutional conditions, such as we have found at SCSH, we must notify the state of those findings and engage in a cooperative effort, through negotiations and consultation, to remedy constitutional deficiencies regardless of cause. It is not our purpose, within the context of CRIPA, to seek redress for past individual incidents, but to ensure that any unconstitutional practices which give rise to such occurrences are permanently eradicated.

I am certain that you and the state personnel with whom we have worked share our concerns, and we look forward to a continuing joint effort to achieve these goals. With these considerations in mind, pursuant to 42 U.S.C. §1997b, we set forth below our findings of conditions which deprive patients at SCSH of their constitutional rights, and the alleged pattern or practice of resistance to those rights, as well as the supporting facts and minimum remedial measures:

Staffing and Staff Qualifications: Our consultants found serious deficiencies in the number of qualified physicians at SCSH. As of April 1984, 28 physicians were responsible for round-the-clock coverage of almost 1100 patients. Not all of these physicians were full time, and some were not qualified in certain areas critical to the proper medical treatment of mental health patients, such as the use of psychotropic drugs. Of the 28 practicing physicians, 18 are psychiatrists. While some had a manageable caseload of 20 to 25 patients, others were responsible for the psychiatric treatment of up to 60 to 80 persons. Similarly, there is an inadequate number of psychologists on the staff. As discussed below, these staffing deficiencies have unconstitutionally deprived SCSH residents of adequate medical care and treatment necessary to avoid undue risks to the patients' personal safety and to assure freedom from unreasonable bodily restraints.

We also found inadequacies in nursing coverage throughout most of the hospital, especially during the evening and night shifts. While some wards apparently have better coverage than others, our consultants noted instances in which one Registered Nurse was covering up to 14 wards, including three forensic wards.

In conclusion, we believe that the current complement of professional and direct care staff is not sufficient to assure that professional judgments are being exercised in decisions affecting patients at SCSH.

Protection from Harm: The deficiencies discussed above have resulted in serious deprivations of the right of patients to be free from unreasonable risks of bodily harm. Patients suffering from severe and sometimes violent psychiatric disorders, who are inadequately or inappropriately treated and supervised, pose a significant danger to themselves and others. Our review of Patient Abuse Reports, dating from January 1982 through January 1984, and of Board of Inquiry records, dating from July 1976 through January 1984, fully supports our finding that these deficiencies subject the patients to unreasonable personal safety risks. These include risks of deaths or injury from patient assaults, aspiration of gastric contents, choking on food, suicide, and improper medical diagnosis and treatment.

Use of Psychotropic Drugs: Our consultants noted serious deviations from accepted professional medical practice in the use of psychotropic drugs. Several physicians interviewed were not well trained in psychopharmacology. For example, a number evidenced difficulty in discriminating between tardive dyskinesia and extrapyramidal side effects. This creates a clear danger to patients since the appropriate drugs to treat acute extrapyramidal side effects might exacerbate the condition of tardive dyskinesia. Some physicians were not aware of the neuroleptic malignant syndrome which is a potentially fatal condition occurring in some patients receiving antipsychotic drug treatment.

While the prescription of several drugs at one time may be appropriate in some circumstances, review of patient records and Board of Inquiry reports revealed numerous instances of inappropriate polypharmacy. Additionally, almost all the patients at SCSH whose charts were examined were on some form of medication, but in many charts the goals and indications for drug treatment were not clear and reasons for changes in medication or dosage were not articulated. These problems are compounded by the reliance on inadequately qualified and supervised direct care staff to administer medication. Overall, the prescribing, administering, and monitoring of psychotropic drugs at SCSH constitute a substantial departure from accepted professional practices.

Restraint and Seclusion: Restraints have been ordered on a nonemergency PRN basis for extended periods without professional evaluation by a physician. In the case of the Forensic Unit, Ward 176, the practice of secluding virtually all patients PRN in nonemergency situations is an extreme example of improper medical treatment which violates SCSH's own standards for issuance of seclusion orders.

Treatment necessary to facilitate the ability of patients to function free from unreasonable bodily restraint is often not provided. The staffing deficiencies previously discussed

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contribute to the failure of SCSH to provide such patients with necessary treatment and thus to the concomitant improper use of seclusion and retraint.

Dates of Occurrence: While it is possible that the above-described conditions have existed for a longer period, our review of records which you have provided, including Board of Inquiry reports, indicates that a pattern or practice of constitutional deprivations has existed since at least 1977.

Minimum Remedial Measures: These conditions represent grave dangers to the health and safety of patients at SCSH. Measures must be taken to bring each of these conditions to the minimum level required by the Constitution of the United States. To this end, appropriate and specific plans must be developed to remedy the deficiencies described above and to maintain adequate conditions in the future. We suggest the following minimum measures:

1. Hiring sufficient numbers of qualified psychiatrists, and other trained professional and direct care staff to ensure, on a continuing basis, that patients are provided with minimally adequate medical care and are not subjected to unreasonable risks to their personal safety.

2. Development of a system through which the appropriateness and safety of patient medical care, particularly psychopharmacological treatment, can be monitored. In this regard, the state should develop and enforce requirements for more stringent recordkeeping; for physician review and approval of assessments and decisions relating to medical care made by nonphysician staff; for recording complete and detailed background information and clinical observations relative to the medical care of patients; and for ensuring that there exists for each patient a record of the course of treatment anticipated and followed, including individual problems and treatment goals. Appropriate equipment to meet necessary medical emergency needs should be obtained.

3. Development and implementation of guidelines for the appropriate use of seclusion and restraint.

4. Development and implementation of such treatment programs as are reasonably necessary to promote patient safety and to keep patients free from undue bodily restraint, including seclusion.

5. Development and implementation of measures adequate to assure staff compliance with hospital policies, protocols, and standards of job performance and behavior relating to the areas discussed above.

I would note that many of our findings and recommendations will come as no surprise to SCSH personnel. Many of these individuals candidly acknowledged the existence of areas requiring improvement. As previously noted, it was clear to us that SCSH employs many conscientious and dedicated staff who strive to provide the best care possible. We would be remiss if we failed to commend these persons for their very substantial efforts.

Again, we want to thank you for your cooperation. Our attorneys will be contacting your office shortly to discuss this matter further and to arrange for future meetings. They will be able to provide your staff with more detailed information. [redacted] I look forward to working with you in a spirit of full cooperation to resolve these matters expeditiously and in a reasonable manner.

& which
we would
be happy
to make our
consultants
available
to help the
state formulate
a specific and
detailed plan for
effectuating
whatever
corrective
measures the
State may choose
to utilize in achieving
constitutionally adequate
conditions at SCSH.
(State Hospital)

Sincerely,

Wm. Bradford Reynolds
Assistant Attorney General
Civil Rights Division

cc: Travis Medlock, Esq.
Attorney General

William S. Hall, M.D.
Commissioner of Mental Health

Ken King, Esq.
General Counsel
Department of Mental Health

Jaime E. Condom, M.D.
Superintendent, South Carolina
State Hospital

Henry Dargan McMaster, Esq.
United States Attorney

SOUTH CAROLINA DEPARTMENT OF MENTAL HEALTH
William S. Hall, M.D., State Commissioner

exhibit 9

[illegible]

For more information contact:
[illegible]
S. C. Department of Mental Health
[illegible]
P. O. Box [illegible]
Columbia, S. C. [illegible]
Telephone [illegible]

155 Years of Healing With Concern

News For Release: NOVEMBER 26, 1984

The Department of Mental Health has received a copy of the U.S. Department of Justice report describing the results of the investigation of South Carolina State Hospital during 1983 and early 1984, covering a period from 1977 through 1983. This highly constructive report cites several Constitutional deficiencies in areas of patient care about which the Department of Mental Health and South Carolina State Hospital have been concerned and actively working to remediate. Dr. Racine Brown, Assistant State Commissioner, has committed the Department of Mental Health to continue fully its cooperation in this joint Federal and State effort. He noted that due to actions taken by the Department and South Carolina State Hospital Director, Dr. Jaime Condom, some of the deficiencies no longer exist.

The Justice report cites:

* a deficient number of qualified physicians, psychologists and nurses to protect the current population of 1,100 patients from harm. These concerns are already being addressed by the following South Carolina State Hospital initiatives:
    (1) A local and nationwide recruitment campaign which has resulted in the hiring of fourteen additional registered nurses and five LPNs since July, 1984.
    (2) A continued reduction in patient census to 700 in 1985.
    (3) A staff reorganization which has improved patient care by grouping patients with common treatment needs and by more appropriately aligning the professional staff to match the eight levels of care which have been identified.
* deficiencies associated with the administration of psychotropic medication. Dr. Condom is arranging for the services of an acknowledged expert in the field of psychopharmacy to evaluate the medication practices and training needs of the South Carolina State Hospital staff. The advice received from this expert consultant will then form the basis for an aggressive training program and procedural revisions if needed.

- that restraints were used for extended periods without professional evaluation by a physician. South Carolina State Hospital implemented a new directive for guidance in the use of restraints in May of 1984. This policy effectively addresses the cited deficiencies and has proven so successful in the course of seven months that it is being made the model for a Department-wide directive which will be implemented in the coming weeks. Additionally, structural changes which are now underway at the SCSH Forensic Unit are enhancing the facility's ability to properly serve the forensic patient population which frequently includes some of the State's most infamous criminal suspects.

Assistant U. S. Attorney General William Bradford Reynolds acknowledged in this letter report that "It was clear to us that South Carolina State Hospital employs many conscientious and dedicated staff who strive to provide the best care possible" and he commends these persons for their very substantial efforts. Mr. Reynolds also offered to make Justice Department consultants available "to help the State formulate a specific and detailed plan for effectuating whatever corrective measures the State may choose to utilize... ." Both Dr. Brown and Dr. Condom expressed their appreciation for the positive and encouraging tone of the report and their confidence that the remaining deficiencies would be corrected. The Department is certain that the Justice Department will recognize the substantial progress which has been made at South Carolina State Hospital under the current administration and those plans which are in place to bring about rapid improvements. The Department is confident that the deficiencies cited will be reconciled to the satisfaction of the U.S. Justice Department and to the benefit of the State's citizenry for whom we serve.

Senator **Weicker.** Our last panel will consist of two of probably the foremost experts in this country relative to many of the problems that we have heard here today: Mr. David Pharis, coordinator of the R.A.J. review panel of Texas; and Mr. Clarence Sundram, chairman of the New York State Commission on Quality of Care for the Mentally Disabled.

Gentlemen, it is nice to have you here. Please proceed directly with your testimony. Mr. Pharis, why don't you start. I might add, your statements in their entirety will be included in the record. So you testify any way you deem fit.

STATEMENTS OF DAVID B. PHARIS, COORDINATOR, R.A.J. REVIEW PANEL, AUSTIN, TX; AND, CLARENCE J. SUNDRAM, CHAIRMAN, NEW YORK STATE COMMISSION ON QUALITY OF CARE FOR THE MENTALLY DISABLED

Mr. **Pharis.** Thank you, Senator. I appreciate the opportunity to address you today. I represent the R.A.J. review panel appointed by the U.S. District Judge Barefoot Sanders to monitor the compliance of a class action lawsuit against the State hospital system administered by the Texas Department of Mental Health and Mental Retardation [TDMHMR].

My comments today will focus upon how the adequacy of staffing, levels of violent behavior, and degree of individualized programming combine either to enhance or inhibit the creation of a benign treatment environment in a psychiatric hospital.

The original lawsuit which created the need for the settlement agreement was filed as a class action suit in Texas in 1974 by family members of patients in several State hospitals. The suit alleged that the constitutional rights of patients were violated in the State hospitals when patients were exposed to danger from harm from other patients, from unsafe physical environments, the misuse and overuse of psychotropic medications, and a lack of individualized treatment.

The State of Texas agreed to a settlement agreement in this case in April 1981. It specifically required that the eight State hospitals in the system would do the following: there would be the protection of patients' rights; the provision of individualized treatment; compliance with life safety code, environment, and accessibility standards for handicapped persons; the development of standards and guidelines for the use of psychotropic medications; and for policies governing patient's consent for medication; appropriate treatment for clients with mental retardation, and the development of after care plans for discharged patients and for a system of after care in the community.

The panel began its monitoring in April 1982, and we report formally to Judge Sanders every 6 months. We have reported in the past that there has been progress in the areas of proper use of psychotropic medications. There has been the development of standards for the use of these medications, and a monitoring system is in place, and we feel that currently they are working within the guidelines.

Also there have been contracts set up for the renovation of facilities to comply with life safety code standards, and there is pr[illegible] in that area.

We filed our third report to the court in December 1983, and we raised concerns about three major areas in that report: lack of individualized treatment, levels of aggressive and violent behavior in the facilities, and inadequacy of staffing. And I will comment a little bit further on each of these.

Senator WEICKER. I would very much appreciate it in both your instances, because you afford to me probably in some respects the most important testimony today, and I do have questions I want to ask both of you because much of your testimony probably will give the shape to the legislation which I propose and which the committee will propose, to synopsize your statement so we will have time for questions. I do have a whole series of questions for you.

Mr. PHARIS. OK, fine. We reported that the type of individualized treatment planning that we were anticipating was not occurring in the facilities. We were looking for treatment that was identifying problem areas and conditions that needed to be improved upon in order for patients to function either in the institution at a better level or be able to return to the community.

We were thinking that that would be based upon the use of psychotropic medications and some psychosocial programming specifically aimed at behavioral problems. We did not find this to be the case.

We also looked into allegations of serious understaffing and high levels of aggressive and violent behavior in the facilities. There were specific complaints about violence. We interviewed the staffs and family members about those complaints, and we conducted a survey looking at the level of aggressive behavior and violent behavior. The findings are presented in my written testimony.

Violent behavior as reported on the surveys included hitting other patients, fights with patients, biting, breaking windows, banging doors, and throwing furniture. Although none of these actions that we found in our review had produced serious injury, there were incidents of serious injury that had been discussed with us in special complaints.

At all the hospitals the major staff interventions around violent behavior were crisis oriented and aimed at bringing an already volatile situation under control. Violent behavior seemed to be considered as just something that often went on with psychosis.

The usual approach for dealing with it was the staff physicially intervening, stopping the situation. Often there was a use of a PRN medication, and often there was seclusion.

We did not find that there were additional therapeutic interventions after the behavior was stopped that was aimed at trying to help the patient learn how to function better. And this was one of the areas that concerned us most. The exceptions to this were behavior modification programs where there was some therapeutic intervention and there was even some talking with patients about why they had gotten angry and acted the way they did, but that was quite rare.

We also looked at the adequacy of staffing. In terms of professional staff, we were concerned about adequacy of nursing coverage, and the duties of registered nurses were primarily administrative in nature. In the rural hospitals there was often a shortage of doctor coverage. With regard to psychologists and social workers, we were concerned more about how these people were being used than about the absence of numbers.

They seemed to be very wrapped up in paperwork and not having the time to be involved in defining the therapy. We were most concerned, however, and we focused most upon the level of mental health worker, aide level staff. We got three months worth of staffing information and analyzed that, reviewed the levels of staffing with some staffing ratio guidelines that we were using. And we were quite concerned that there was inadequate coverage.

We were particularly concerned about the numbers of single mental health worker coverage on wards. We considered that there should be no circumstances when a single staff member should ever be on duty alone.

We considered single coverage to be very dangerous both to patients and staff. A single staff person cannot simultaneously deal with the needs of 20 or 30 patients. They cannot deal with suicidal patients. They get separated from other staff with the physical setups of the buildings, and it is just an extremely serious situation.

Lone staffing on the wards was not a rare situation at the time that we looked. Out of the 124 wards in the hospital system 77 of them had had single staffing occurring in the 3-month period that we were looking at. Several of them had it occurring routinely.

Some staff told us that they were quite comfortable being alone on duty; they were not threatened by it. Others clearly were.

The concerns raised by this report led to an evidentiary hearing in Judge Sanders court in February of 1984. And it resulted in a finding of noncompliance with the settlement agreement in the three areas that I have mentioned.

Since then there has been plans for correcting each of these issues, an elaborate plan on trying to bring the staffing ratios under control. The judge ordered that there never be less than two mental health workers on duty on any ward at any one time. And he also ordered that a 5-to-1 ratio for the 2-day shifts and a 10-to-1 patient to staff ratio for the night shift be achieved over a year's period of time.

The other orders and plans included the development of programs for aggressive behavior and for programs that would implement the individualized treatment.

We have gotten some information about the types of programs that have been implemented for aggressive behavior, and we have been happy with some of these. Basically there are two different types. There are verbal therapies that are being implemented either at an individual or group level and behavior modification programs.

Generally people are in State psychiatric hospitals because they are severely mentally ill, are considered to be dangerous to themselves or others, and unable to function well in the basic areas of daily living. There are currently treatment methods which are very helpful in alleviating the worst manifestations of illness and in helping people to grow and to improve their functioning. These include the appropriate use of psychotropic medications and a range of psychosocial programming. In order for human dignity to be maintained and in order for these treatments to be effective patients must be living in a safe environment.

This requires a sufficient number of staff to deal appropriately with the types of aggressive, violent behavior that many of these people present. The methods for dealing with these behaviors exist. It is necessary to provide these treatments. Mental hospitals are labor intensive organizations. It takes a lot of staff to run these organizations well.

We believe that standards need to be enforced to address these issues. To do less is to devalue their lives.

[The prepared statement of Mr. Pharis follows:]

STATEMENT BY DAVID B. PHARIS, COORDINATOR
R.A.J. REVIEW PANEL

Prepared for the United States Senate
Subcommittee on the Handicapped
United States Senate Committee on Labor and Human Resources
April 1, 1985

Mr. Chairman, Members of the Committee. I am David Pharis, Coordinator of the RAJ Review Panel. I appreciate the opportunity to address you today to discuss issues relevant to the implementation of a settlement agreement aimed at improving the conditions of patients in the state hospitals run by the Texas Department of Mental Health and Mental Retardation (TDMHMR). The RAJ Review Panel was appointed by United States District Judge Barefoot Sanders to monitor compliance of TDMHMR with the requirements of this settlement agreement in April, 1982. The other two members of the panel are Martha Boston, an Austin attorney, and James Peden, M.D., a psychiatrist at Timberlawn Hospital in Dallas.

My comments today will focus upon how the adequacy of staffing, levels of violent behavior, and the degree of individualized programming combine either to create or inhibit the creation of a benign treatment environment in a psychiatric hospital. First I will explain programmatic requirements of the settlement agreement and the subsequent criteria used by the Panel during site visit reviews. Then I will briefly present findings which lead to further court action, and finally I will discuss the components of a therapeutic treatment setting.

The original lawsuit was filed as a class action case in 1974, under the name of Jenkins vs. Cowley, by family members of patients in several state hospitals. The suit alleged that the constitutional rights of patients were violated in the state hospitals when patients were exposed to danger from harm and unsafe physical environments, to the misuse and overuse of psychotropic medications, and to the lack of individualized treatment programming.

The plaintiffs in the case were defined as all former, present, and future patients at the eight state hospitals. The State of Texas agreed to a settlement of this case in April, 1981, which specifically required:

- The protection of patients rights;
- Individualized treatment planning and programming; and sufficient staff to provide 30 hours per week of appropriate planned activities per patient;
- The renovation of hospital buildings for compliance with life safety code, environmental and accessibility standards for handicapped persons;
- The development of standards and guidelines for the use of psychotropic medications and for policies governing patient's consent for medication;

- The development of specialized treatment programs in the state hospitals for those patients with mental retardation who need inpatient psychiatric hospitalization;
- Appropriate placement or discharge for those patients with mental retardation who no longer need inpatient psychiatric hospitalization;
- The development of aftercare plans and services for discharged patients, and development of a system for continuity of care within the state.

TDMHMR agreed to attain and maintain accreditation by the Joint Commission on Accreditation of Hospitals (JCAH). TDMHMR also agreed to seek all necessary funding to implement this settlement agreement when it signed the agreement in 1981.

Implementation of the above requirements of the settlement agreement was initially envisioned to require three years. The Review Panel reports formally to the Court every six months, and at this point has issued five of these reports and three special reports. The Settlement Agreement, the Supplemental Agreement and Order for the appropriate use of Psychotropic Medications, and the Third Report to the Court are submitted as references to this testimony.

The Review Panel considered the Settlement Agreement, subsequent implementation plans, JCAH Standards, and relevant TDMHMR policies as the criteria for measuring compliance. Schedules for compliance and methods for measurement were developed for each of the major areas of the Settlement Agreement.

In the area of individualized treatment planning and programming the Panel interpreted the language of the Settlement Agreement and relevant JCAH requirements to mean that treatment would be composed of a combination of the appropriate use of psychotropic medications and appropriate psychosocial programming provided by an interdisciplinary team. The psychotropic medications would be used to control the symptoms of psychosis and the major affective disorders and the psychosocial treatment would be aimed at addressing deficits in social, vocational, and inter-personal functioning. Individualized treatment was conceived as meaning the identification of problem areas, conditions, or functioning capacities, which needed to be changed or improved in order to permit the patient to function in a less restrictive environment. The rationale or explanation of why a particular intervention was useful to the particular patient was seen as the key to individualization.

In the Third Report to the Court filed in December 1983, the Review Panel reported that it was increasingly concerned about the effectiveness of the treatment which patients were receiving. In the previous two Reports to the Court, the Panel had expressed concern about the lack of individualization of problem descriptions, the broadness of a problem description, and the formulaic approach to treatment strategies. Although the Review Panel was sure that much staff time was expended in treatment planning, we questioned whether this effort was translated into meaningful service for the patients. Having reviewed a sample of individual treatment plans in all eight hospitals, the Review Panel concluded that for the most part, patient records did not reflect thoughtful problem identifications followed by thoughtful intervention programs. In most units, every patient had the same set of interventions prescribed, regardless of the nature of the problem described. Far too often, the interventions did not appear to logically relate to the problem.

At the time that the Panel was reviewing records for evidence of individualized treatment it was also having to investigate allegations of serious under-staffing and high levels of aggressive or violent behavior in the hospitals.

During the summer of 1983, the Review Panel was contacted by patients and relatives of patients, about alledged incidents of violent behavior in several of the hospitals. The Panel examined specific case situations through conducting interviews and also conducted a survey in each of the facilities to determine the degree of violent or aggressive behavior occurring on the wards.

The investigation of violent incidents focused upon the type of behavior, what the staff did to handle the situation, and whether violent behavior had been addressed as a problem in the patient's individual treatment plan. Chart A presented the survey findings on the occurrence of violent behavior. The following data referred to six of the eight hospitals. Data for the other two hospitals was presented separately on Chart A. 102 patients out of the 278 patients (37%) whose records were read were physically violent to some degree. These patients had 310 separate acts of violent behavior during the review period. 61 (60%) of the 102 patients with incidents of violence had violent or aggressive behavior mentioned as a problem in their treatment plan.

The violent behaviors reported on in the study included hitting other patients, fights with patients or staff, biting, breaking windows, banging doors, and throwing furniture. None of these actions were terribly serious, although serious violent behavior had occasionally occurred.

At all the hospitals, almost all of the staff's interventions around violent behavior were crisis-oriented and aimed at bringing an already volatile situation under control. Violent behavior seemed to be considered as a component of and being caused by the patient's psychosis, i.e., patients sometimes strike out in response to their hallucinations or delusions. The usual approach for handling these behaviors was PRN medication and seclusion. These interventions were therefore reactive rather than proactive and preventive in nature. There was little indication of attempting to develop a therapeutic environment which neither fostered or tolerated violent behavior; and there was little evidence of systematic therapeutic efforts to alter behavior patterns and re-socialize patients.

Exceptions to this were some behavior modification programs. In several of these programs, aggressive or destructive behavior was more likely to be addressed in the patient's treatment plan as a problem, with a subsequent set of strategies for eliminating the negative behavior and encouraging more appropriate behavior. In one behavioral program, it was in fact apparent that after episodes of violence the staff would talk to the patient about why he/she had become angry and how he/she could have handled the situation in a better way.

As the Review Panel formulated its concerns about the lack of active programming in the facilites and investigated the incidences of violent behavior, serious question was raised about the adequacy of staffing patterns. Staffing information was gathered on all professional and direct care personnel for the months of June, July, and August 1983.

Charts B and C show the average patient to staff ratios for mental health workers and nursing staff for the month of August 1983. The Review Panel was particularly concerned about the adequacy of mental health worker staffing because they are the group most responsible for maintaining safety on the ward. The Review Panel used a 5:1 patient/mental health worker staff ratio on the two day shifts and a 10:1 patient/mental health worker staff ratio on the night shift as criteria for minimally adequate staffing for a safe environment. These ratios were based upon some staffing standards which had been considered but not adopted by TDMHMR. It was quickly apparent from Chart B that the 5:1 and 10:1 patient/staff ratios for mental health workers were not being met. The exceptions to this were children's and adolescent units, and the multiple disabilities unit at one hospital.

The Review Panel considered single coverage to be totally unaccpetable. Under no circumstances should a single staff member be on duty alone - even at night.

Single coverage is dangerous to both patients and staff. A single staff person cannot simultaneously deal with the needs of 12-30 patients; and obviously, a lone staff person is unprotected in a violent situation. The architectural construction of the building contributes to the inadequacies of single staffing. In buildings with very separate dorm areas, the single staff is very isolated from other staff. Routine duties such as checking on secluded or restrained patients every 15 minutes, dispensing medication, providing 1 to 1 coverage of suicidal patients, or taking a patient on any trips will immediately occupy one staff person per task.

Lone staffing of a ward was unfortunately not a rare situation. Based upon the August staffing data, at least 77 wards out of 124 wards in the state hospitals (62%) were identified as having shifts which were staffed by one person. Actually this incidence of single staffing was more frequent than was first realized because of variations in ways that hospitals reported data.

Although very concerned about the adequacy of mental health worker staffing, the Panel also questioned the adequacy of professional staffing as well. This is described in the Third Report. There was concern about the adequacy of nursing coverage and that the duties of registered nurses were primarily administrative in nature. There was also concern that there was often a shortage of doctors in the rural hospitals. Generally the Panel considered adequate numbers of psychologists and social workers and was more concerned about how these staff were used than by the absolute numbers of staff. The Panel was interested that these staff were used to enhance individualized programming.

The Review Panel's reports have indicated continued progress towards compliance in the areas of use of psychotropic medications and compliance with life safety code standards. The Third Report to the Court issued in December 1983 alleged noncompliance in four areas: 1) development of individualized treatment plans; 2) protection of patients from harm 3) provision of adequate staffing to acheive both individualized treatment and protection of patients from harm; and 4) requirements for placement of patients with mental retardation.

An evidentiary hearing was held in February 1984, and in April 1984, Judge Sanders issued an order finding noncompliance in the first three areas (above). The Court specifically ordered that there would be no less than two mental health workers on duty on any ward on any shift and that the hospitals achieve and maintain the 5:1 and 10:1 patient to staff ratios. A plan for remedy was developed by the parties and the Panel and approved by the Court which outlined how each area of noncompliance would be addressed. Court-ordered staffing ratios were to be achieved by August 31, 1985, through the hiring of staff, the reduction of patient census, or a combination of both. Agreed-upon definitions of individualized treatment were to be developed and implemented. Programs for aggressive behavior were to be put in place in each hospital unit, and the incidence of aggressive behavior was to be monitored.

The Review Panel has been impressed with some of the new programs for modifying aggressive behavior in the hospitals, and believes that if properly implemented the agreed-upon concepts of individualized treatment and the proposed revisions of the case record system can greatly improve patient care. The Review Panel has also recognized the achievement of the first step in improvement of patient/staff ratios.

Serious question, however, has been raised about whether the reduction of patients in the hospitals is being accompanied by appropriate aftercare planning and referral of patients to adequately staffed community services. This question was explored in a Court hearing with Judge Sanders on March 8, 1985.

There is also serious question about whether sufficient funds for compliance will be provided in the 1986-87 legislative budget appropriations process.

Generally people are in state psychiatric hospitals because they are severly mentally ill, are considered to be dangerous to themselves or others and unable to function well in the basic areas of daily living. There currently are treatment methods which are very helpful in alleviating the worst manifestations of the illnesses and in helping people to grow and improve their functioning capacities. These include the appropriate use of psychotropic medications and a range of psychosocial programming. In order for human diginity to be maintained and in order for these treatments to be effective, patients must be living in a safe environment. This requires a sufficient number of staff to deal appropriately with the types of aggressive/violent behavior that many of these patients present. The methods for dealing with these behaviors exist. It is necessary to provide sufficient numbers of adequately trained staff to provide these treatments. Mental Hospitals are labor-intensive organizations. It takes a lot of staff to run these organizations well. We believe that standards need to be enforced which address these issues. To do less is to devalue the lives of the patients in institutions.

CHART A

REVIEW OF VIOLENT INCIDENCES DURING AUGUST - SEPTEMBER, 1983

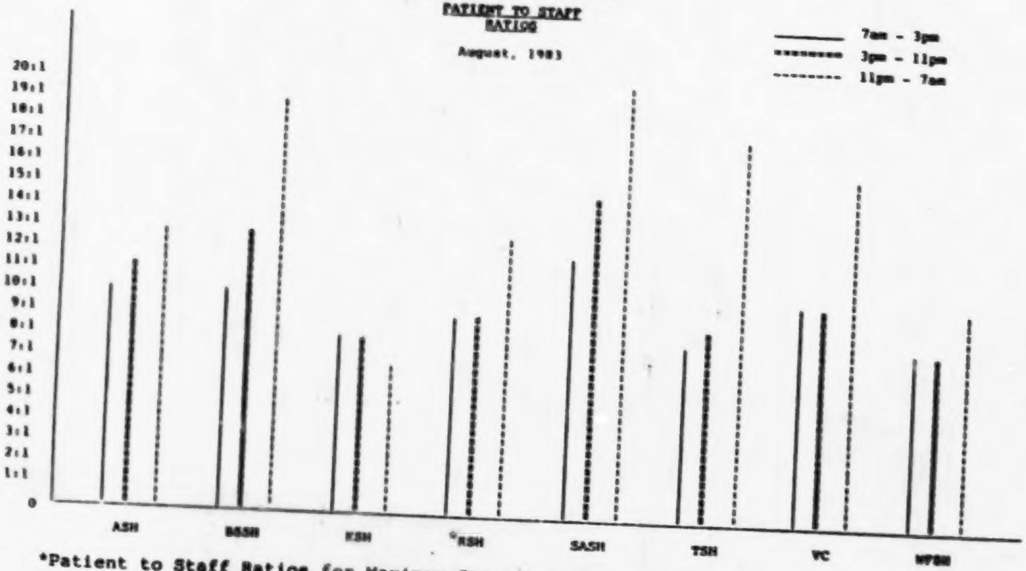
Hospitals:	# of Record Read	# of Violent Incidences	# of Pts. Violent	# Addressed in Indiv. Treatment Plans
Austin	48	99	22	3
Big Spring	34	63	17	5
Kerrville	32	0	0	0
Rusk				
-Valley View	53	34	15	8
-Max. Security	20	10	4	4
San Antonio	66	83	29	26
Terrell	25	21	15	15
TOTAL	278	310	102	61
Vernon*	88	33	25	17
Wichita Falls*	40	38	35	10
TOTAL	126	71	60	27

* A different sampling method was used at Vernon Center and Wichita Falls State Hospital, cases were identified from Injury Incident Reports.

Chart B

M.H.W. STAFF
GENERAL PSYCHIATRIC UNITS
PATIENT TO STAFF RATIOS

August, 1983



*Patient to Staff Ratios for Maximum Security Units:

1st Shift: 11:1
2nd Shift: 11:1
3rd Shift: 16:1

Chart B

M.H.W. STAFF
GERIATRIC UNITS
PATIENT TO STAFF RATIOS

August, 1983

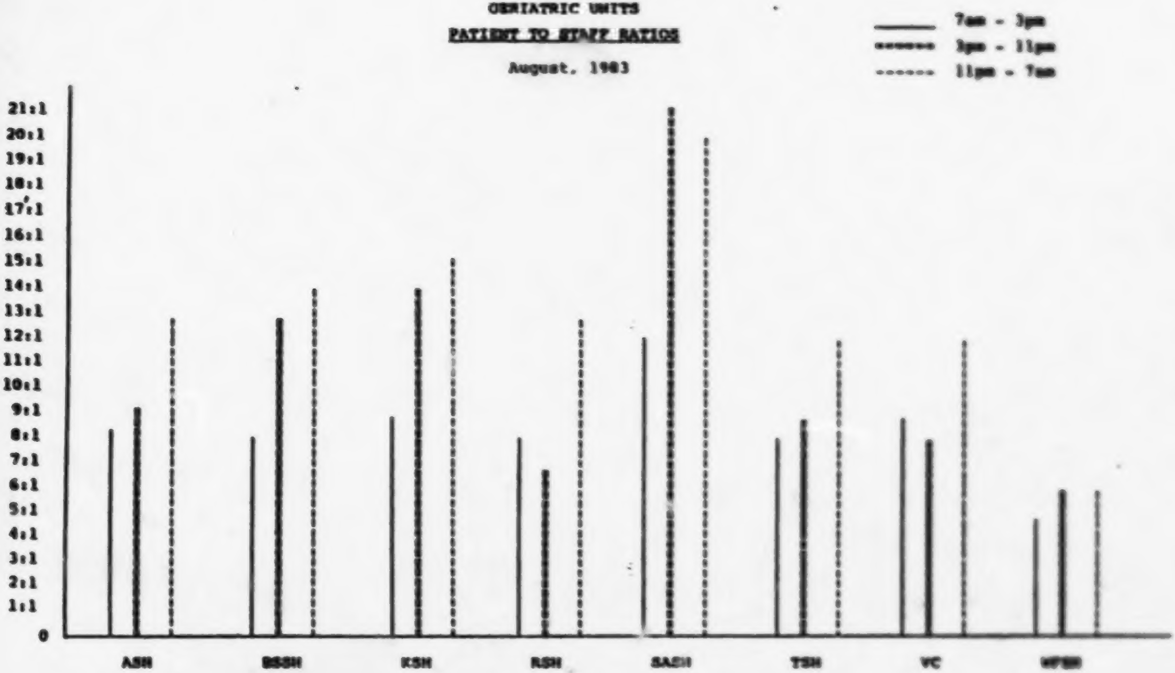


Chart B

M.H.W. STAFF
CHILDREN'S UNITS
PATIENT TO STAFF RATIOS
August, 1983

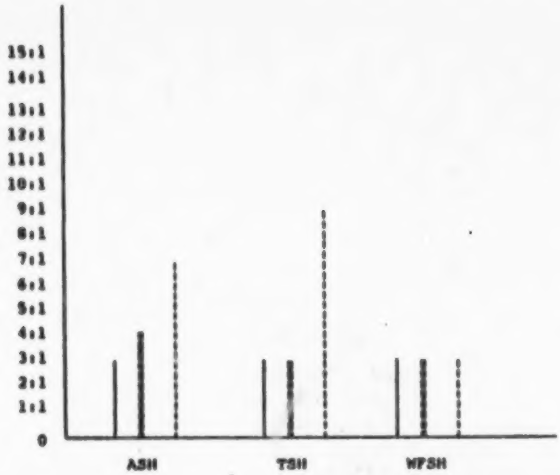
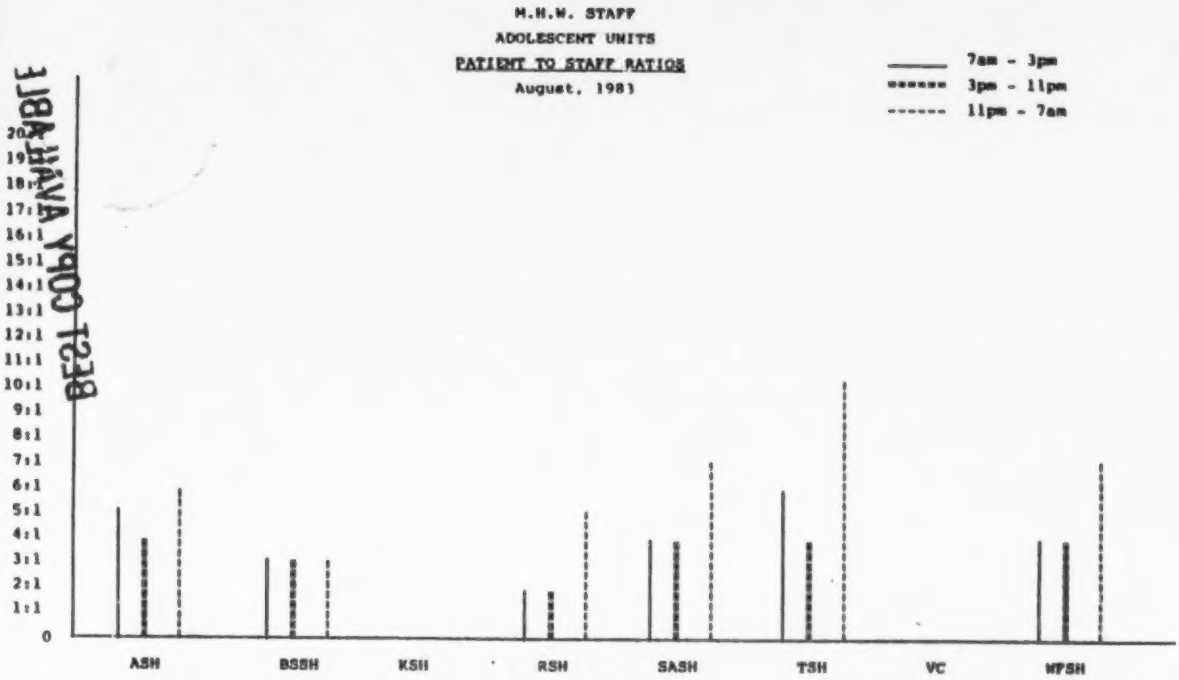


Chart B



M.H.W. STAFF
ADOLESCENT UNITS
PATIENT TO STAFF RATIOS
August, 1981

Chart B

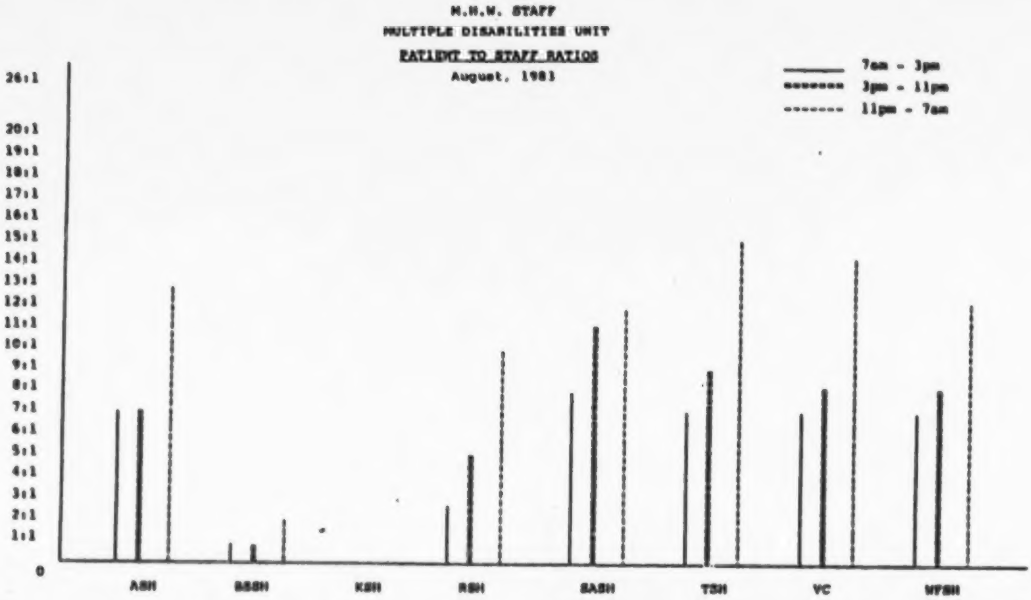

M.H.W. STAFF
MULTIPLE DISABILITIES UNIT
PATIENT TO STAFF RATIOS
August, 1983
7am - 3pm
3pm - 11pm
11pm - 7am
26:1
20:1
19:1
18:1
17:1
16:1
15:1
14:1
13:1
12:1
11:1
10:1
9:1
8:1
7:1
6:1
5:1
4:1
3:1
2:1
1:1
0
ASH
BSSH
KSH
RSH
SASH
TSH
VC
WFSH

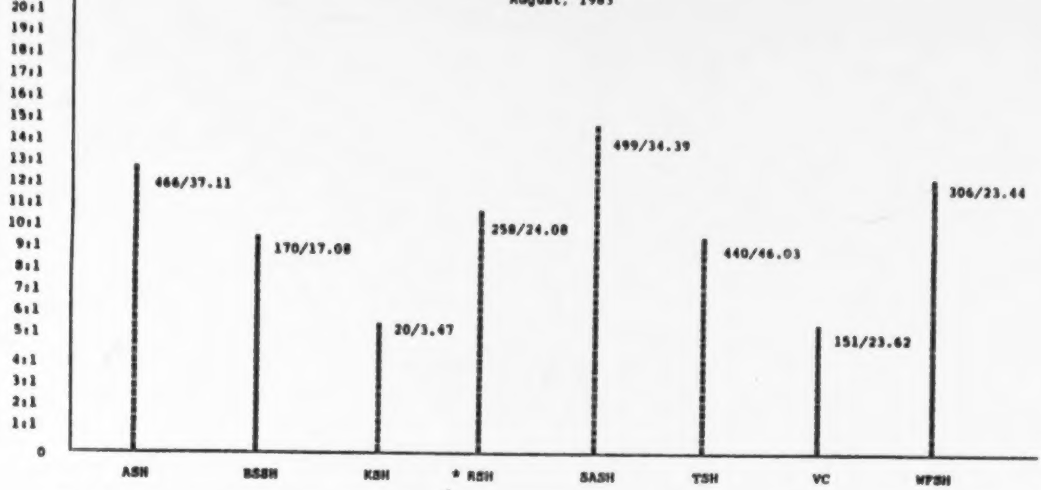
Chart C

RN/LVN STAFF

GENERAL PSYCHIATRIC UNITS

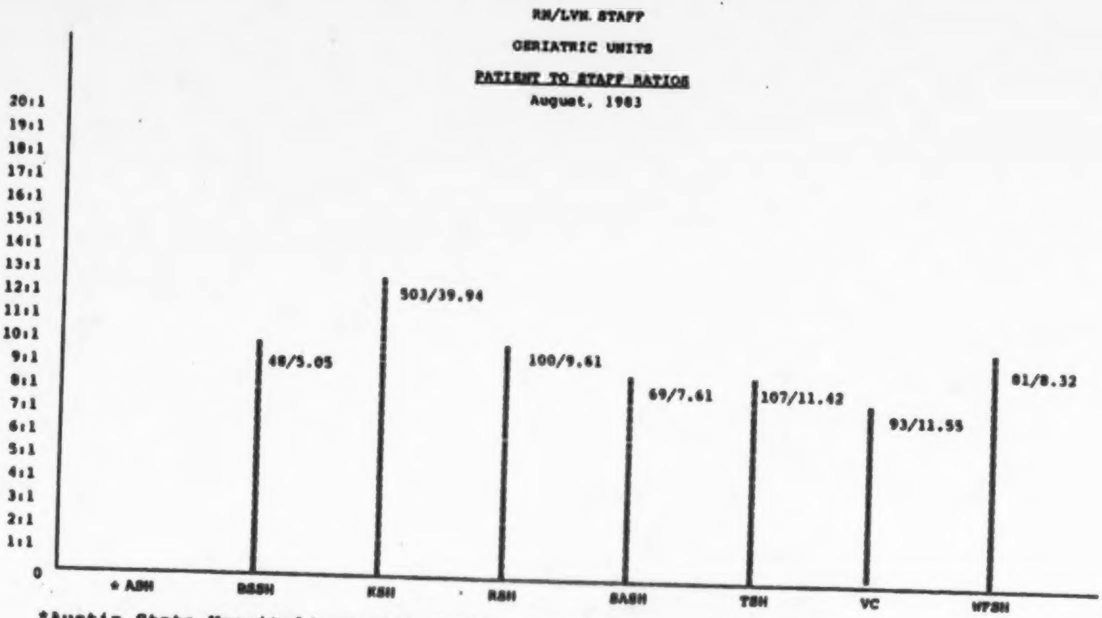
PATIENT TO STAFF RATIOS

August, 1983



*Patient to Staff Ratio for Maximum Security Units: 14:1

Chart C



RN/LVN STAFF

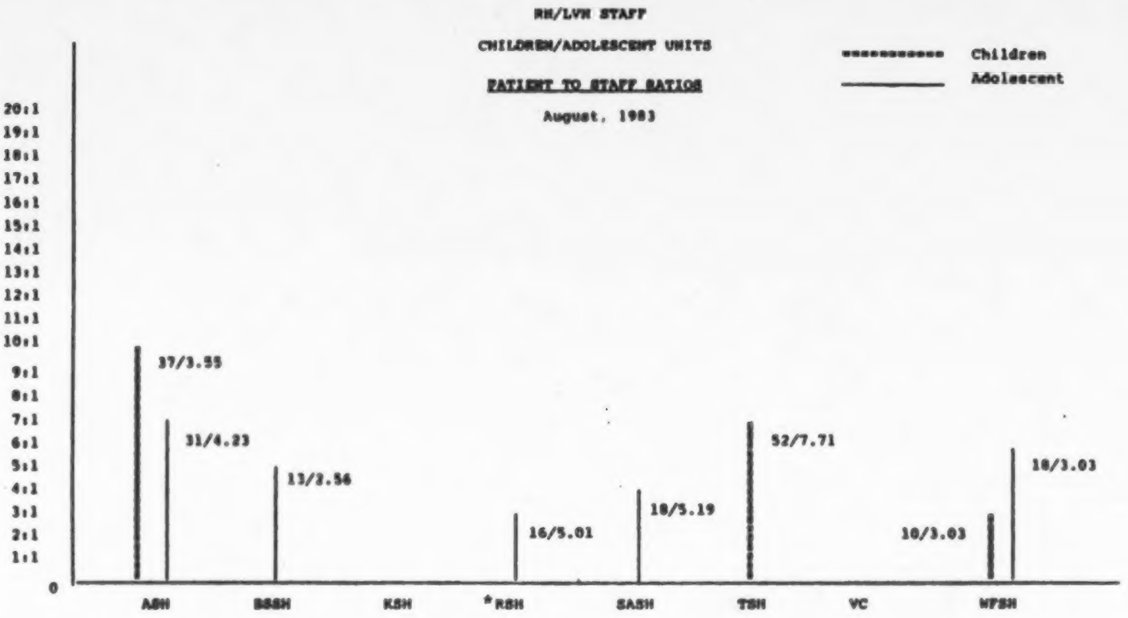
GERIATRIC UNITS

PATIENT TO STAFF RATIOS

August, 1983

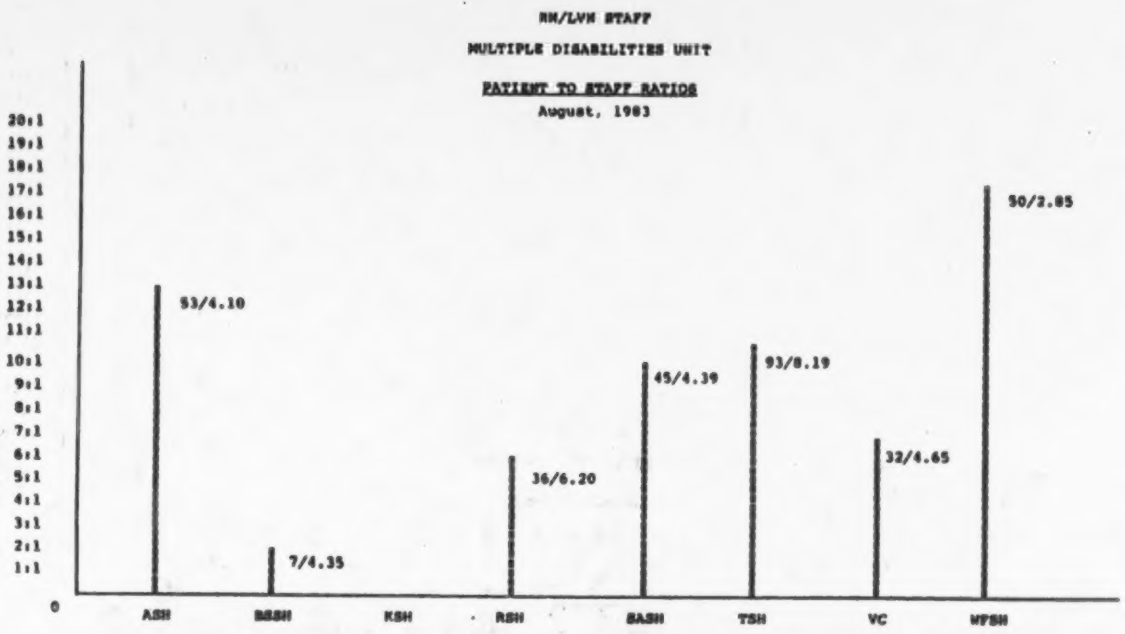
*Austin State Hospital's Geriatric Unit staffed with General Psychiatric Unit staff.

Chart C



* Rusk State Hospital's Children's and Adolescent Units staffed together.

Chart C



RN/LVN STAFF

MULTIPLE DISABILITIES UNIT

PATIENT TO STAFF RATIOS

August, 1983

R.A.J. REVIEW PANEL
authorized by the
UNITED STATES DISTRICT COURT
NORTHERN DISTRICT OF TEXAS
Honorable Barefoot Sanders

DAVID B. PHARIS,
M.S., M.C.R.P.
Coordinator
MARTHA L. BOSTON,
Attorney
Panel Member
JAMES K. PEDEN, M.D.
Panel Member

March 20, 1985

Senator Lowell Weicker, Jr.
SH 303 Hart Senate Office Building
Washington, D.C. 20510

Attention: Tracy Crowley

Dear Senator Weicker:

Enclosed is a copy of my testimony prepared for the Subcommittee on the Handicapped of the United States Senate Committee on Labor and Human Resources on April 1, 1985. I am also enclosing a copy of the R.A.J. Settlement Agreement, the Supplemental Agreement concerning guidelines for the use of psychotropic medications, and the Panel's Third Report to the Court as reference material to the testimony.

I am looking forward to testifying on Monday, April 1, 1985.

Sincerely,

David Pharis

David Pharis, A.C.S.W.
Coordinator

DP:dms

Enclosures (4)

cc: Judge Barefoot Sanders

(EDITOR'S NOTE: In the interest of economy, the above mentioned R.A.J. Settlement Agreement and the Panel's Third Report were retained in the files of the Committee where they may be researched upon request.)

Senator **Weicker**. Thank you very much, Mr. Pharis. I will be coming back at you with some questions.

Mr. Sundram, it is a pleasure to have you with us.

Mr. **Sundram**. Thank you. I am the chairman of the New York State Commission on Quality of Care for the Mentally Disabled, which is an independent agency created by the State legislature to oversee the largest institutional community based service system in the country.

Our functions include the investigation of deaths in mental hygiene facilities, allegations of patient abuse and neglect, and complaints regarding the quality of care. Under State law we have access to facilities at any and all times. We have access to records and employees and the authority to issue and enforce subpoenas and to take testimony under oath. We also administer the protection and advocacy program for the developmentally disabled.

These experiences have provided some insight into the nature of the problem of patient abuse in institutions about which I have been asked to testify. Patient abuse is like a cancer in a facility; it has many causes only some of which we know about.

Undetected and unchecked it can metastasize rapidly and pollute the therapeutic environment. Checking this scourge often requires radical surgery which itself is not risk free.

However, the risk of not acting is even more unacceptable. Let me begin by recognizing the plight of the mentally disabled person who has been institutionalized. Often cut off from contact with family and friends, isolated from the community and with few realistic options to be elsewhere, institutionalized persons are among the most powerless individuals in our society. They depend daily on employees for their most basic needs.

They and their families are at the receiving end of a power relationship, and they are deeply fearful of the consequences, real or imagined, of complaining about employees.

And of course their very status as institutionalized individuals casts a shadow on the competence and credibility of anything they have to say, particularly when it may be easier not to believe them.

They live in a world where time and space are frequently irrelevant. Many facilities do not even have clocks and calendars that are accessible to patients. Yet when allegations of abuse are made, in the ensuing legal proceedings which may occur months later, times, dates, and places are crucial elements of evidence making patient witnesses uniquely vulnerable to disintegration on the witness stand.

Let me illustrate these observations by relating a case history. An 11-year-old child in a children's psychiatric center was allegedly struck on the legs with a broomhandle and a stick by two therapy aides after the child had dumped two dinner trays on the floor. The next night one of the nurses noticed the child crying; he showed her the bruises on his thigh and told her he had been hit the day before. The following day, a Saturday, when his mother visited he showed her the bruises and told her he had been hit.

The unit chief met with the mother, the two employees who had allegedly struck the patient, and two other employees. All the staff members denied that the abuse took place. Later that day one of the accused employees accompanied these children on a trip to a restaurant. As they were getting on the van he asked if any of the children had seen the abuse occur. All the children denied having seen anything and the employee reportedly said, "Good; there would be real trouble otherwise."

The next day, a Sunday, several children asked for a meeting with the nurse and told her about the abuse they had witnessed and about the subsequent threat. Ten days later the two employees were suspended and disciplinary charges were filed which resulted in an arbitration hearing.

There were 4 days of hearings over the next 4 months. In deciding the case the arbitrator noted that the victim's testimony was not coherent. While the victim stated that he had been abused, he could not remember the exact date of the abuse.

Another 11-year-old witness who testified to the abuse was confused about the time of occurrence and about the time when he first reported it to anyone else. Two other children were called as witnesses, but they refused to talk.

The employees testified to the effect that the children had made up the whole story. The arbitrator concluded that the children's testimony was not credible because of confusion over the dates and times and the delay in reporting the abuse. The employees were then reinstated to their positions.

This anecdote illustrates many of the problems with reporting abuse, investigating and prosecuting it, and devising effective remedies. Many of the factors that lead to the occurrence of patient abuse in the first place, particularly to the kind of minor abuse, the hair pulling, the pinches, the shoves, the slaps, and other physical abuse that does not lead to permanent injury, this kind of abuse, the circumstances that lead to it also preclude its reporting.

What are the factors? Let me summarize a rather lengthy elaboration at this point. First of all it starts with staff recruitment, with training and supervision. In most States these jobs are civil service jobs where the sole qualification for employment is taking a civil service test and the score determines whether you are hired or not.

Many of these facilities also have extremely inadequate training programs that do not prepare the employees for the foreseeable consequences or circumstances they are going to encounter on wards; for example, dealing with violent staff. As a result, when staff encounter a patient who is going into a psychotic episode and becoming violent, they resort to their street skills in trying to subdue the patient, not with a trained response.

The results of this kind of behavior have often been tragic. We have investigated a number of cases in New York State where patients were acting out and were restrained by staff, and when the restraint was completed the patient was dead.

The third point has to do with supervision. We hire therapy aides. We put them on the wards, and they are usually there by themselves. The professional staff are busy in their offices filling out paperwork to make sure the Federal funds keep flowing by documenting everything they are supposed to document.

The therapy aides deliver most of the care and are for all intents and purposes abandoned on the wards, particularly after normal business hours.

Most of the abuse that occurs in institutions generally speaking occurs on the second shift, the one from 3 o'clock to 11 o'clock when all the professional staff have gone home and the patients are awake, there is a lot of staff-patient interaction, and abuse occurs.

Now, part of the reason why abuse occurs in institutions has to do with the working conditions. You walk into these wards of the institutions and ask yourself if you would like to spend a day there. They are depressing. They are onerous places. They are bad for the staff and they are bad for patients.

I think the combination of depressing working environments, the absence of professional staff, who are the ones making the real money, sends a signal to the direct care staff on the wards that the patients are not terribly valuable to anybody.

You combine that with understaffing, overcrowding, and work that is emotionally and physically exhausting, employees who very often are asked to work double shifts because somebody did not show up to work, and you have created a climate, I think, where there is a tremendous tendency for exasperation to occur.

Most of the abuse that occurs in institution is that kind of behavior, shoving a patient who does not move fast enough when you want to shower him, a patient who is too slow eating, slapping his hands, slapping his face. This kind of stuff goes on all the time. And, unfortunately, what happens when this kind of behavior occurs and other staff see it, they all understand what motivates the behavior and they realize that if the abuse was reported the employee who did the abuse would be dismissed, but nobody would deal with the underlying problem of the working conditions. So a conspiracy of silence develops where employees are protecting one another because they are all in a boat by themselves and there is no captain.

These kinds of working conditions are things that are, generally speaking, tolerated by the higher-ups in a facility. So you have a climate in which minor abuse is tolerated.

With the minor abuse being tolerated, you develop a climate where it becomes a natural response to the exasperation of every day to slap a patient to cope with the bad behavior. And it is very easy for that threshhold of minor abuse to be stretched to more major behavior as the pat[illegible] acting out becomes more difficult or the short staffing on the ward becomes even more problematic. So you create a climate in a ward where much serious abuse can occur as well.

Generally speaking in my experience the staff who work in institutions, while they may tolerate the pushing and shoving and slapping of patients, do not have a lot of sympathy for major assaults on patients, for sexual abuse of patients, for any of the real serious harm that is caused to patients.

But there are some very powerful factors that go on in institutional society that prevent those kinds of behaviors from being reported even though the witnesses, the employee witnesses may not approve of what they are seeing.

What are these factors? Well, to start with what is the director's attitude going to be towards somebody who has committed an act of abuse? That is a very important factor. Is the disciplinary system even handed? That is an important factor. Is it effective? That is crucial. And what is the kind of investigation that is going to occur if the abuse is reported?

Let me take you through a chronology. The director's attitude: When you talk to most directors of facilities, and I am sure your staff has, and the common thing they will tell you is that they do not tolerate any patient abuse. If they catch anybody abusing a patient he is out the door. It is a wonderful statement and they probably mean what they say.

Unfortunately, when you look at the behavior of most of the directors, they are the very ones who have tolerated the kinds of working conditions that I just described, which everybody knows leads to abuse.

They also make very little attempt—the rare director makes an attempt to inculcate a sense of value about human dignity of patients. They make even less of an attempt to encourage reporting in a way that anybody feels free to make reports. But, sure enough, if a report does come to their desk they will seek dismissal of the employee who has been reported.

Let me tell you a story. I went to see a facility for the mentally retarded in New York, and as I was touring the facility I asked the director, "Do you have many complaints of abuse?" He said, "Well, we had one a few weeks ago. This employee took a T-shirt and struck a female patient across the face with a T-shirt. But do not worry, we are going to get rid of him."

So as I asked some more questions to find out more about the circumstances it turned out that this was a ward of 25 profoundly retarded male and female patients, many of whom were nonambulatory. There were two therapy aides on duty on this evening shift for these 25 patients. And the patient in question was a 25-year-old female who kept ripping off her blouse.

She ripped it off three times before the employee struck her. The first time she took it off he put it back on her. The second time she took it off he put it back on her.

The third time she took it off he struck her across the face and said, "God damn it, keep your shirt on." As it happened, somebody was walking by and saw the act and they brought this person up on charges. I asked the director, has this patient had this behavior for a long time. He said, oh, yes, she has been doing that ever since she got here.

Do you have a behavior modification plan to get rid of this behavior? No, we have not gotten around to doing that. If you had walked by here and the patient was sitting exposed, what would you have done? Well, we would have brought the guy up on discipline charges for that. So I said, don't you think there is responsibility somewhere else here as well for this kind of behavior? And if you are going to fire this person for this act of abuse, which is tantamount to capital punishment for a petty offense, what are you going to do when you catch somebody with something really major?

He said, gee, we had not thought about that. But that kind of an attitude tells all the other employees that if they report one of their peers for an act of abuse they are in effect imposing a death sentence on their colleagues and it may not be justified.

The second point has to do with evenhandedness. The nature of institutions is such that job descriptions for people who do the direct care work are very specific. You will feed the patients; you will clothe them; you will bathe them; you will do whatever, which is fairly tangible. Professional staff have much vaguer job descriptions. And when you are talking about discipline of people, you are talking about a legally oriented process. And when you have vaguer job descriptions it is much harder to hold anybody accountable.

And by and large the disciplinary mechanisms in institutions target the people who are the bottom echelon of the institutions who can most easily be nailed. And they rarely ever focus on the responsibility of higher-ups. And if you have an instance where a director targets a supervisor or a professional staff person, they usually have the option of leaving and going someplace else and getting a job somewhere else, and usually they will get a clean letter of reference to facilitate their exit from the institution.

So you have a problem with a lack of evenhandedness and a disciplinary machinery that by and large focuses on the most powerless echelon of the staff in an institution. But perhaps most important is the question of effectiveness. If I am an employee and I witness an abuse occurring, I have a terrible choice to make. I can keep my mouth shut and pretend I did not see anything and the chances are nothing will ever happen. Or I can report it, and if I report it I am likely to be ostracized by every other employee and I am likely to face reprisals as well. Well, that might be a price worth paying if there is any point in reporting it, if something is going to happen to the person who committed the abuse.

Well, in New York State and many other States the disciplinary process is a very structured, legally oriented process with rules of evidence, and so on, and you have to go through arbitration. And it is the exceptional case in which an arbitrator will impose a penalty of dismissal on any employee unless he has been caught doing something really flagrant or it is a repeated act of abuse.

So, by and large, when the disciplinary proceeding is over the employee retains his job. He may be gone for a few weeks, but he is going to be back. So the employee faces the prospect of working alongside somebody whom he has put through all this turmoil and it is going to be a very unpleasant experience for the person who has filed the complaint.

Patients face that same problem. They are in even a worse situation because they are dependent on the employees. They are, as I said before, at the receiving end of a power relationship. And if they make a report, aside from having their credibility questioned because they are patients in an institution and somebody has decided that they are not fit to live in society, so who can believe them; they also have the wrenching ordeal of being cross-examined on the witness stand where their entire clinical history can be used to impeach their testimony.

So, not surprisingly, there are relatively few circumstances in which charges that have been brought by patients are ever sustained or where anybody ever loses his job as a result of a complaint of patient abuse.

The last point has to do with equality of investigations. In most places the investigations are done by the personnel guy or the supervisor of the unit who has little or no training in how to conduct an investigation and perhaps not much incentive to conduct an investigation because very often the causative factors that may have led to the act of abuse are a failure of supervision or a failure of management.

Where clinical people do these investigations there may be a very strongly held belief that the investigation itself is not therapeutic for the patient because of the ordeal the patient is going to have to go through. So the vast majority of investigations, whether consciously or unconsciously, follow the path of least resistance and wind up with a conclusion that the allegation cannot be substantiated, and therefore nothing is ever done.

With this kind of a disciplinary machinery, it is not surprising that there are not a good deal of incentives for either employees or patients to file complaints of abuse.

[The prepared statement of Mr. Sundram follows:]

PREPARED STATEMENT OF CLARENCE J. SUNDRAM

Mr. Chairman and Members of the Committees:

I appreciate the invitation to testify before this Committee to assist in assessing the quality of care in public institutions for the mentally disabled. I am Chairman of the New York State Commission on Quality of Care for the Mentally Disabled, an independent agency created by the Governor and the Legislature to oversee the largest institutional and community-based network in the country for individuals with mental disabilities.

The Commission's functions include investigations of deaths in mental hygiene facilities, allegations of patient abuse and neglect, and complaints regarding the quality of care. We have statutory access to facilities at any and all times, access to records and employees, and the authority to issue and enforce subpoenaes and to take testimony under oath. We also administer the Protection and Advocacy System for the Developmentally Disabled and I serve as Vice-Chairman of the New York State Developmental Disabilities Planning Council.

These experiences have provided some insight into the nature of the problem of patient abuse in institutions about which I have been invited to testify. Patient abuse is like a cancer in a facility. It is deadly, yet difficult to detect or cure. It has many causes, only some of which we know about. Undetected and unchecked, it can metastasize rapidly and pollute the therapeutic environment. Checking this scourge often requires radical surgery, which itself is not risk-free. However, the risk of not acting is even more unacceptable.

Let me begin by recognizing the plight of a mentally disabled person who has been institutionalized. Often cut off from contact with family or friends, isolated from the community, and with few realistic options to be elsewhere, institutionalized indiviudals are among the most powerless people in our society. They depend daily on employees for their most basic needs. They, and their families, are at the receiving end of a power relationship, and they are deeply fearful of the consequences, real or imagined, of complaining about employees. And, of course, their very status as institutionalized individuals casts a shadow on the competence and credibility of anything they have to say, particularly when it may be easier not to believe them. They live in a world where time and space are frequently irrelevant. Many facilities don't even have clocks or calendars easily accessible to patients. Yet, when an allegation of abuse is made, in the ensuing legal proceeding, which may occur months later, times, dates and places are crucial elements of evidence, making patient-witnesses uniquely vulnerable to disintegration on the witness stand.

Let me illustrate these observations by relating a case history. An 11-year-old child in a children's psychiatric center was allegedly struck on the legs with a stick and a broom handle by two therapy aides after the child had dumped two dinner trays on the floor. The next night one of the nurses noticed him crying. He showed her the bruises on his thigh and told her he had been hit the day before. The following day, a Saturday, when his mother visited, he showed her the bruises and told her he had been hit. The unit chief met with the mother, the two employees who had allegedly struck the patient, and two others. All the staff members denied the abuse took place. Later that day, one of the accused employees accompanied a group of patients on a trip to a restaurant. As they were getting out of the van, he asked if anyone had seen the abuse occur. All the children denied having seen anything and the employee reportedly said "Good. There'd be real trouble otherwise."

The next day, a Sunday, several children asked for a meeting with a nurse and told her about the abuse they had witnessed and about the subsequent threat. Ten days later the two employees were suspended and disciplinary charges were filed which resulted in an arbitration hearing. There were four days of hearings over the next four months. In deciding the case, the arbitrator noted that the victim's testimony was not coherent. While the child clearly stated that he had been abused, he could not remember the exact day the abuse occurred. Another 11-year-old witness testified to the abuse but was confused about the time of occurrence and about the time when he first reported it to anyone else. Two other children were called as witnesses but refused to talk. The employees testified to the effect that the children had made up the story. The arbitrator concluded that the children's testimony was not credible because of confusion over dates and times and the delay in reporting the abuse. The employees were reinstated to their positions at the facility.

This anecdote illustrates many of the problems with reporting abuse, investigating and prosecuting it, and devising effective remedies. Many of the factors that contribute to the occurrence of patient abuse in the first place, particularly to minor abuse (hair pulling, slaps, shoves, pinches and other physical abuse that does not lead to lasting physical injuries), also preclude its accurate reporting. What are these factors?

Staff recruitment, training, and supervision. There is limited flexibility in hiring for most positions in state institutions, which are part of the civil service merit system. Applicants generally qualify for employment by taking a competitive civil service test. Typically, especially in direct care positions, the test score is the primary criterion for employment. The background and experience of applicants for direct care positions are given only a cursory screening, and a potential candidate's temperament is not examined. As a result, persons with low frustration thresholds and explosive personalities are not screened out.

Compounding the limited discretion of hiring practices is the absence of an adequate employee training program to equip new employees with the skills necessary to cope with certain foreseeable conditions, such as violent behavior by patients. Over the past seven years, for example, the Commission has investigated a number of deaths of state hospital patients that resulted from violent confrontations with ward staff. In practically every instance, one or more of the staff attempting to restrain the patient had had no training in dealing with violent patient behavior despite often lengthy employment at the hospital. In the absence of employee training, the use of retaliatory, excessive, and occasionally deadly force has occurred.

The reality of little effective supervision of direct care staff by professionals, particularly after normal business hours, further compounds the problems resulting from inadequate preemployment screening and inservice training. Most incidents involving abuse occur during a facility's second shift (3 p.m. to 11 p.m.) while the patients are still awake but most professional supervisors are absent. Even during regular business hours, the most highly trained and highly paid staff are the farthest removed from direct patient contact and are often inaccessible to direct care staff in need of their assistance and guidance. Staff learn most clearly by example. If their superiors have little contact with patients, what is being communicated to direct care staff about the value of working with patients?

Working conditions. The environment in which patients live and staff work can play a significant role in the presence or absence of abusive behavior. Physical environments that are dreary and dismal and lacking in humanizing touches communicate silently yet eloquently the lack of respect for the human dignity of those who must live and work there. When such conditions are allowed to exist, as they do in many institutions, particularly in urban areas, they contribute to a sense of isolation and abandonment of the inhabitants by the larger society. Thus, despite the values of care and compassion that we write into our laws, rules and regulations, policies and procedures, the quality of life for patients and staff is determined to a considerable extent by the dynamics created by working and living conditions.

In many state hospitals, understaffing is a chronic problem that is frequently exacerbated both by overcrowding and by unscheduled absences of direct care staff. It is not uncommon for three or four therapy aides, and sometimes less, to be primarily responsible for meeting the multiple and conflicting demands of 30 to 40 patients, with little support from their supervisors. Among the aides' duties are helping to bathe, clothe, feed, and sometimes toilet patients; measuring and administering medications several times a day; providing one-to-one supervision for the patients who need it; escorting patients to activities and clinics off the ward; providing activities on the ward; and documenting a variety of important and unimportant occurrences.

Mandatory overtime and double shifts are part of the job when administrators attempt to cope with unanticipated staff absences. The demands on ward staff have been made even more physically and emotionally exhausting by the deinstitutionalization of most of the stabilized patients and the emergence of the actively psychotic young adult chronic schizophrenic patient as a significant segment of the patient population. We expect therapy aides to have the wisdom of Solomon, the patience of Job, the caring of Florence Nightingale -- all for wages of a janitor.

Under these working conditions, it is altogether understandable that powerless direct care staff, who are at the bottom of the institutional hierarchy, who perform the most difficult work, and who are the lowest paid, experience anger and frustration. Often, the most available outlets for these feelings are the patients, who are probably the only group more powerless than direct care staff and who are also the least capable of retaliation.

Most abuse that occurs in institutions results from acts of frustration and exasperation rather than from sadistic behavior. This type of abuse -- slapping a patient's hands or face for grabbing or spitting food, pushing patients into their chairs, shoving a patient who doesn't move fast enough, yelling derogatory epithets -- occurs most frequently during periods of greatest staff-to-patient interaction, such as during the feeding, bathing, and dressing of patients, when the cumulative effects of understaffing, varied job demands, and difficult patients are most acutely felt.

Adverse working conditions are experienced by all direct care staff and most of them therefore understand what motivates minor abusive conduct. Because direct care staff see themselves as victims of a larger system that would be quick to punish them for minor abuses but that is slow to recognize and improve the adverse working conditions that contribute to abusive behavior, at most they will merely caution an abuser not to repeat a behavior. Minor offenses are rarely reported to superiors, except by visitors, trainees, or the patients themselves; by a fellow employee who feels personal animosity toward the abuser; or by other staff who have become convinced that the abusive behavior is excessive in its frequency or degree and beyond the informal, unarticulated norms that exist among the peer group.

Since minor patient abuse is rarely reported, few staff are ever punished for it. Given that, and the conditions under which staff work, there are currently no general or specific deterrents to this type of patient abuse. Worse yet, such behavior can become a learned response to the stress of the workplace, much as an abusive parent falls into a pattern of striking a child for minor misbehavior. Undetected and unchecked, such abuse can become part of the patient's daily living experience. Once a climate is created where minor abuse is tolerable and accepted, there is a constant risk that the invisible threshold of acceptable abusive behavior will be crossed again into the realm of more significant abuse as the stress of the workplace increases, either because of difficult and violent patients or because of an exacerbation of chronic staffing shortages.

The so-called code of silence that exists for minor abuse of patients does not generally extend to major abusive behaviors such as sadistic behavior, sexual exploitation, or serious injuries to patients. Ward staff generally have little sympathy for such behavior, to some extent at least because the effects are more likely to be apparent.

Because such major abusive behavior lies outside informal staff norms and is less accepted by staff, it is less likely to occur in front of witnesses. But even when such behaviors are witnessed, there are powerful factors at work in institutions that hinder prompt reporting of severe patient abuse by employees as well as by patients. These factors include the facility director's attitude toward employees charged with allegations of patient abuse; perceptions of staff about the evenhandedness of the disciplinary system as applied to professional and direct care staff; and the effectiveness of the disciplinary machinery in punishing alleged abusers.

The director's attitude toward alleged abusers. Several facility directors have stated that no patient abuse is tolerable and that it is their intent to seek dismissal of any employee who is believed to have committed an abusive act. But, while they say this and probably mean it, they often allow deplorable environmental and working conditions, that contribute to the occurrence of abuse, to exist. They do not actively work to inculcate a sense of values about human dignity that would help prevent abuse. And it is the exceptional facility director who makes aggressive efforts to encourage the reporting of abuse when it occurs. Ironically, their reaction when confronted with a report of patient abuse may deter employees from filing such reports.

Some time ago, during a visit to a facility for the mentally retarded, I asked the director if they had had any recent reports of patient abuse. He said they had a report about an aide who had been observed by a supervisor to strike a female patient across the face with a tee shirt. He assured me they were seeking the dismissal of the employee. But, the more I learned about this episode, the less I was convinced of the wisdom or justice of this course of action. In response to my questions, the director informed me that the aide was one of two on duty on a ward of 25 severely or profoundly retarded individuals, several of whom were non-ambulatory. The female patient who was struck had a propensity for disrobing and had removed her tee shirt three times immediately preceding the incident. After the first two episodes, the aide had helped her put back her shirt. But the third time, he struck her with the shirt, saying "Goddamn it, keep your tee shirt on!" It further turned out that, although this patient's tendency to exposė herself was well known, no attempt had been made in her treatment plan to deal with this behavior. It thus fell to the therapy aides to keep the patient appropriately dressed, under pain of discipline, despite the lack of any professional assistance.

This director's response to the abuse puts him on the side of the angels when it comes to dealing with families and patient advocates. But is it fair or wise to seek the capital punishment of the workplace for a non-severe act of abuse occurring under mitigating circumstances?

Under New York State law, the disciplinary process is established through collective bargaining and is embodied in the labor contract. The grievance machinery reposes ultimate disciplinary power not in the facility director but in an arbitrator jointly selected by the state and the union from a mutually approved list. The director may propose, but the arbitrator disposes. Thus, the director's decision to seek dismissal for every transgression, regardless of the severity of the offense, the employee's prior record or extenuating circumstances, generally has three effects, all of them counterproductive. First, he will be unlikely to prevail in this recommendation in all but the most egregious cases of proven abuse or repeated misconduct. Second, his recommended penalty of termination will soon cease to carry any weight with the arbitrator who will surmise, sometimes correctly, that the director is simply passing him a political hot potato rather than making an honest attempt to find a punishment proportionate to the transgression. Third, the willingness of employees to report instances of abuse will be adversely affected since they recognize that such a report is tantamount to a death sentence for a co-worker.

To the extent that a director is perceived as seeking discipline tailored to the gravity of the offense, he is more likely to impress the arbitrator, prevail in his position, and eliminate an unnecessary barrier to the reporting of abusive incidents.

Staff perceptions of the fairness of the disciplinary process. Closely related to the director's attitude toward ward staff who are charged with patient abuse are the perceptions of staff about the evenhandedness of the disciplinary system in dealing with professional staff. Does the system follow the path of least resistance and target the trainee, the probationary employee, or the lowest level employee to bear the brunt of the responsibility for abusive behavior? Or does the disciplinary process conscientiously attempt to define supervisory responsibility for any lack of training and supervision that may have contributed to the abusive incident?

Direct care staff often have reason to conclude that the former attitude is far more prevalent than the latter. Job descriptions for ward staff are usually far more specific and detailed than those for professional staff, which provide considerable latitude for acceptable behavior and make it more difficult to pin down failures of supervision or training to specific duties. In a legally oriented disciplinary process, ward staff are therefore more susceptible to discipline for breach of a defined duty than are professional staff. Furthermore when the invocation of a disciplinary sanction appears imminent, most professional staff have considerably greater employment options than ward staff and are assisted in some cases by assurances of a clean letter of reference. If the disciplinary machinery is perceived to grind down the powerless while leaving the more powerful unscathed, direct care staff have no incentive to provide colleagues as fodder for this machine.

Staff perceptions of the effectiveness of the process. Even more important perhaps than the previous two factors is the employee's perception of the effectiveness of the disciplinary system once its operation is triggered. The employee who is an innocent witness to an incident of patient abuse is faced with a terrible choice: he can do nothing about it and become a silent accomplice, subject to disciplinary sanctions himself for failure to report the incident, or he can report the abuse, risk the wrath of and perhaps reprisals from the abuser, and face ostracism by fellow employees who do not approve of his action. The likelihood of discovery in the former instance is not great, but the negative effects of the latter course of action are likely to be real and immediate. Will the disciplinary system be effective in dealing with the abuser or will it fail, leaving the employee who reported the abuse in the uncomfortable and even untenable position of working alongside the abuser?

The employee-witness often confronts a difficult choice between doing the right thing and doing the wrong but prudent thing. The available evidence indicates that only a small percentage of cases of reported abuse ever reach the arbitration stage and, even if the employee is found guilty of an act of patient abuse, there is a substantial probability that he will not be terminated from employment but will eventually resume his patient care duties.

Quality of investigations. One of the most important reasons for the poor results is the ineffectiveness of the disciplinary system in investigating reported allegations of patient abuse. At most facilities, the responsibility for investigations of abuse rests with clinicians or personnel officers who have little or no training in such a task. Although legal rules of evidence are not strictly applied in arbitration proceedings, the failure of personnel officers to appreciate the importance of having witnesses available for cross-examination or of establishing a chain of custody for physical evidence has lost many a case.

The investigators' lack of training is compounded by the inherent difficulty of investigating co-workers with whom one has had prior and possible future working relationships. The investigators may also bear indirect responsibility for some of the conditions that may have contributed to the environment in which the abuse occurred. And underlying those difficulties may be a strongly held view that the investigation itself is likely to be antitherapeutic for the victim and for other patient-witnesses.

Like employee-witnesses, patient-witnesses are placed in the difficult position of having to choose between silence and accusing an employee who is likely to remain on the ward and in a position to retaliate. If patients do choose to accuse an employee, the ensuing disciplinary proceeding may be a substantial ordeal particularly since, as with most due process proceedings, lengthy delays are inevitable. Confidential clinical records may have to be disclosed to facilitate cross-examination.

In the end, few disciplinary cases supported solely by the testimony of patients are successful. Given all these factors, it is not surprising that patients have demonstrated little enthusiasm for reporting abusive behavior.

The standards of proof used in disciplinary proceedings and the strains on investigators, witnesses and patients combine to produce investigations that usually terminate inconclusively. There is reason to suspect, however, that in addition to these very real problems, and perhaps because of them, facility directors have a fairly powerful and probably subconscious inclination to follow the path of least resistance. Barring any outcry by families or patient advocates, many will conclude an investigation with a decision of "allegation unsubstantiated," which avoids the inevitable confrontation with the labor union. Based on the preliminary data that it collected, the Commission estimates that nearly four out of five investigations into allegations of patient abuse in New York State facilities result in such a conclusion.

The poor results of investigations into reports of abuse and the failure of prosecutions when investigations conclude that abuse occurred simply reinforce the message to victims and witnesses of abuse that discretion in reporting may indeed be the better part of valor. The end result at present is that there is little real deterrence to abusive behavior, be it minor or severe.

Conclusion

It seems to me that the conditions which allow patient abuse to occur have been ingrained into the fabric of institutional life over decades and, in my opinion, there are no easy and lasting "quick fix" solutions. Nevertheless, there are a number of actions that can be taken by the states to reduce the existing problem of patient abuse. Many of them are being undertaken in New York State including the development of new tools for screening prospective employees; better training programs for staff; employee assistance programs; creating special investigator titles in institutions and providing training in investigative techniques; improving the disciplinary process; and making a concerted effort to upgrade the conditions in institutions.

But, as I have indicated, the seed of the problem lies in the nature of institutions themselves and in our historic over-reliance on them to deal with the problems of mental disabilities. The contribution the federal government can make to the reduction or elimination of the problem of abuse is to provide incentives for states to change these long-ingrained patterns of behavior and to develop more community-based residential and treatment alternatives for mentally ill people, much as has already been done for the developmentally disabled. I do not mean to imply that community facilities are immune to the problem of abuse. They are not. But their existence in the community and the contact their residents have daily with others in work programs and clinics provide a number of valuable safeguards. First of all, the residents are not isolated but are seen regularly by different pairs of eyes which can detect any obvious problems. Second, the residents have the opportunity to build trusting relationships with others outside the facility which may lower the barriers to reporting of abusive conduct. Third, when residential and program staff are in separate sites and even separate agencies, the "code of silence" does not become as significant a problem. Finally, since these facilities do not have the self-sealing qualities of institutions, and abuse is easier to detect and address, the risk of discovery and sanctions does create a deterrent effect to such conduct occurring in the first place.

I understand that the concern over the federal deficit may preclude major expansion of programs like ICF/MR to the mentally ill as well. If that is so, consideration should be given to authorizing major demonstration programs to test the comparative quality and cost effectiveness of community-based residential and treatment alternatives to institutions.

I would also suggest that there is a need for a mechanism similar to the Developmental Disabilities Planning Councils to provide for interagency planning at the state levels in a variety of housing and human services agencies that deal with mentally ill people. Like the DD Councils, this mechanism would receive and distribute federal funds for innovative approaches to meeting critical needs of mentally ill people in the community, in accordance with planning priorities arrived at in a fully participative process.

Finally, I am a believer in the power of effective advocacy. I think there is a critical need for a Protection and Advocacy System for people with mental illness. This program has proved its effectiveness on behalf of the developmentally disabled and can provide desperately needed assistance to the mentally ill as well. I believe the condition of patient care would improve considerably from an articulation of patients rights, coupled with an accessible source of assistance to which patients and their families can turn, without fear of reprisals.

Thank you.

271 Corona, # 3
Long Beach, California 90803
April 1, 1985a
(213) 433-8363

Senator Lowell Weicker, Jr.
Hart Senate Building, Suite 303
Washington, D.C. 20510

RE: MENTAL HEALTH INVESTIGATION

Dear Senator:

This morning I read that you are investigating the plight of the mentally handicapped in state institutions. Enclosed find a copy of a recent letter to our California Senator which indicates some of the frustrations of working in a state hospital. I would like to direct your attention to some of the conditions at Metropolitan State Hospital, especially those affecting the deaf and physically handicapped. I attempted to use the 1973 Rehabilitation Act to alter conditions at the hospital in the face of administrative statements that this was a political issue. Since I started at Metro in 1981, a blind staff member filed a 504, I filed one for the deaf patients, a multiple amputee filed one for a ramp and was refused, I filed one to have two wheelchair patients moved to an accessible ward, and a final one was filed when I was fired a few days after the state Office of Civil Rights informed the hospital administration that they were out of compliance. I attempted to file another complaint about the placement of a convicted felon with a history of several rapes and murders on a ward where he previously had raped several women. The government refused that complaint. There is a need for a responsive government agency, possibly an improved Office of Civil Rights, to answer complaints about the mentally handicapped, because the defendant in such actions is a state institution, and is defended by the Attorney General of the state. County Grand Juries lack jurisdiction.

Asylums, a classic by Erving Goffman of Berkeley, on the total institution was helpful to me in understanding how the back ward and the privilege system works. It still works that way, with the same attendants and the same patients, untouched by the revolving door of the 72 hour stay and the right to a writ. My experience in a meat warehouse in Chicago many years ago also went a long way in aiding my understanding of how institutions function.

In the 504 filed more than two years ago with the Department of Health and Human Services' Office of Civil Rights, Alberto Valdes was named as a handicapped person who had been deprived of auxillary aids, appropriate education and rehabilitation, and equal treatment. Mr. Valdes has received tutoring in sign language to remedy the more than twenty years of neglect he underwent after being misdiagnosed as severely retarded when he was eight years old. He evidently received therapy for a period of a few months after the complaint was answered. He does not now. He continues to be inappropriately placed on a locked ward, because this particular back ward is designated by management as the repository of deaf males, though his behavior is generally adequate for placement on an open ward with higher functioning people. His placement with the lowest functioning people in the hospital is upsetting to him. On this ward, there is no telephone device for the deaf; he has never been taught to use one, anyway. There is no television decoder for the deaf on that ward, which also might help his spelling and reading skills. When the hospital was developing their program for the deaf, only agencies who contracted with the hospital and were friendly to the administration were allowed input. The hospital has refused to advertise for a psychologist who signs. The only change in the life of Alberto Valdes is that a Mr. Watts teaches him sign language now. Mr. Valdez used to sign at length and with feeling about his desire to speak with the judge about being kept in the hospital. He always knew his next court date, but never saw the judge. He has the right to a jury trial over his conservatorship each year. He has not received a trial before a judge in more than three years because of his communication disorder, or possibly because of his potential for embarrassing the administration. He appears happier, but overmedicated. He grinds his teeth and does not respond to signing about going to court anymore. I went to several meetings concerning his legal status while on the staff, and found that he was eligible for a great deal more aid in the community than he would ever receive in the hospital, since he is a Regional Center patient. The same Public Guardian, the same Regional Center representative, the same judge, and the same administrators conferred, but Valdes never got a trial. He does not answer direct questions well, but his behavior is better than many of the dangerous and helpless men who are discharged every day. Most of his problem at this time is being confined to a back ward, since he is a source of trouble to the state because of a suit taken out years ago by Mental Health Advocates. Signs on his chart direct all personnel not to speak to anybody about the patient, and I found social workers, doctors, and psychologists are not allowed to have contact with his family or any agencies concerning this man. His case docket number in OCR was 09-82-3236. Much of what was written as a plan of correction was mere paperwork stating policies. The measure of reform in treatment is human beings interacting with him in a treatment setting appropriate to his needs, both for remediation of the iatrogenic communications disorder which he suffers as the result of his misdignosis more than twenty years ago, as well as his mental illness and his sensory defect. His performance I.Q. has been measured as high as 81 in recent years, but was around 30 when he was consigned to Fairview as a child and placed with the retarded until he attained his majority, when he was transferred to the forensic facility at Atascadero without committing a crime. He then went to Camarillo, where staff wrote he did not belong and where they admitted there was no program for him. He has been at Metropolitan ever since, where the administration has systematically kept him from getting adequate treatment, deprived him of his right to a jury trial, and placed him with the lowest functioning people in the hospital. This man should be on an open ward with communication devices and have a psychologist who conducts his therapy in sign language at conversational speed in a therapy room free from interruption. He needs a social worker who attempts to involve the family and the community in treatment and placement, rather than one who covers up for the hospital. If people on the staff are forbidden to talk about the man's problem, who is going to know? What is going to be done? I sent in the complaint, they filled out the paperwork, and he did get a tutor. He didn't get anything else, such as a chance to get out, and I got fired. His "job" in the hospital has been going on for years, and he still gets fifty cents an hour. It doesn't prepare him for anything, and it is the only job available in the total institution.

The canteen is still inaccessible to the handicapped who hop and crawl up the stairs, as is the volunteer center, where the pool table is on the second floor. There was a wheelchair at the bottom of the stairs on many days.

May I suggest decentralizing the organization of the state hospital so that a physician is the representative of management and also provides professional guidance in the daily conduct of each ward? At this time, a senior attendant reports to a "program director" who is on site once a month for physical inspection. The ward is run by attendants who resent the influx of professionals.

It is common to have a psychologist administer tests to prospective police officers to screen out those who may not be able to withstand the stress of the job. If this is necessary with police who work in the public eye, how much more necessary can it be for those who work out of sight with the most helpless and frustrating people in America? I suggest this screening for both attendants and institutional police officers.

Thus far, I haven't found it to be too effective to write complaints; there is a clever doctor in the administration who answers them without doing anything concrete, and another clever doctor who goes on television and smiles while saying the whole problem is lack of money. An article on the abuse of the authority of medicine appeared in Psychiatry in 1982 by J.R. Lifton of Yale, called the "Medicalization of killing." This concerned the doctors who decided who was to live or die in concentration camps, as well as the role medicine plays in fronting for the total institution, the analogue in American life to those "terminal placements" another wealthy industrialized nation provided for the handicapped, the socially unacceptable, and those totally unable to fend for themselves.

Please let me know if there is anything I can do to further your investigation in general, or the case of Alberto Valdes, since the 504 appears ineffective.

Thank you for looking into a situation most avoid in a nation increasingly oriented toward the needs of the rich, the well born, and the able.

Sincerely,

Edward F Fischer, Ph.D.

Edward F. Fischer, Ph.D.
Licensed Psychologist

cc. Senator Weicker – Mental Health

271 Corona, #3
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March 22,1985
(213) 433-8363

Senator Alan Cranston
5757 West Century Boulevard
Los Angeles, California

OFFICE OF CIVIL RIGHTS ACTIONS RELATING TO HANDICAPPED MENTAL PATIENTS AND PROTECTED ACTIVITIES

Dear Senator Cranston:

While working as a psychologist at Metropolitan State Hospital in Los Angeles County, I had occasion to write complaints to the Office of Civil Rights of the Department of Health and Human Services concerning refusals by the administration of the State Hospital to provide equal services to handicapped patients.

My duties as a psychologist included: "evaluate and report on current and new programs; serve as consultant within the agency or to other agencies and groups; may work with community groups to develop supportive resources...and initiate, design, collaborate and report on psychological research and program evaluation."

The Los Angeles County Grand Jury has stated it lacks jurisdiction to investigate conditions at the State Hospital because it is a state institution. The Attorney General of the State of California defends the State Hospital, so my only recourse has been to the Federal Office of Civil Rights. Several 504 complaints had been filed in the past, and the requisite paperwork dutifully completed by the appropriate administrators, but no programs for the deaf were ever implemented for more than a few months.

All of the deaf patients were housed on a locked back ward with the most regressed long term patients in the hospital. I went through channels such as the Patients' Rights Office, Mental Health Advocates, and the director of the program to which I was assigned. I requested a television decoder device, a telephone device for the deaf, and the presence of a technician who knew sign language to assist me in group therapy. I experienced denials of these legitimate requests for equal treatment of handicapped patients, as well as harassment from my direct supervisor, Carl Hanssen, M.D., who expressed his opinion that this was a political issue unrelated to my duties. After exhausting the avenues open to me within the institution and alienating management by having made such requests, I filed the 504 complaint in October 1982 and included several other deficiencies in the deaf project.

I also assisted a multiple amputee in filing his own complaint for wheelchair access to the canteen after the Patients' Rights office refused his request. He regularly crawled up the stairs to the canteen building. OCR refused to investigate because he indicated there was a ramp in the rear for deliveries, though this was inadequate for wheelchairs and there was no question of a person using it independently. OCR reopened the complaint, then disposed of it when Dr. Hanssen wrote that they would put in a doorbell so that the librarian could allow the patient into the library and out the back door, where he could then then ring a bell at the back door of the canteen, which he could then enter with assistance. This was a lawful solution, OCR found. Patients still hop and crawl up the stairs if they want to get in. The library is closed on weekends.

OCR informed me that the other access questions which I had mentioned in discussion with them would have to form a second complaint. This complaint involved the inaccessible telephone and water fountain on ward 406, as well as an inaccessible washroom which had a spring loaded door with a turning handle and a short step up. Two patients were issued urinals to hang on the arms of their chairs, which they occasionally used in public. After the complaint, the patients were transferred to a ward with an accessible washroom, and Dr. Hanssen reported that the patients preferred to have urinals and denied ever using them in public. Since this was "voluntary" on the part of these incompetent patients, there was no basis to the allegation. The patient who made the complaint lived under these conditions for several years. OCR concluded that all of the allegations were false, since the hospital moved the patients to an accessible ward.

The staff of ward 406 had a policy of allowing male and female patients to use the same washroom, as there was only one male washroom in the common area of the ward, and women could not go to the washroom unless somebody unlocked the door to their dormitory. Several women complained of being raped in that washroom, four of them by a prisoner on parole assigned to the ward who had raped and murdered at least twice in the past. When he was finally transferred off the ward because of his behavior, Dr. Hanssen had him transferred back a month later, as he belonged on 406 because of the length of his stay and his catchment area in the city, a classic example of the warehouse approach to hospital administration. He was then charged by two other women of sexual molestation before being discharged as an embarassment to the hospital. OCR refused this complaint, as did another federal agency to which I was referred by OCR.

As a result of this complaint, chronic women and men are housed in separate wards at this time, which dramatically reduced the number of rapes in the hospital. The hospital indicated to OCR that this was done for "reasons of safety."

All these patients with their diverse needs and vulnerabilities were assigned to the same ward on the basis of their geographic catchment area and length of stay, or because they were deaf, since the only technicians who knew sign language were on that ward. Many of the deaf people were higher functioning and should have been on open wards.

So things are getting better at the state hospital in Los Angeles. There is a doorbell Monday thru Friday for people in wheelchairs, handicapped patients are assigned to an accessible ward, a program for the deaf exists on paper, and the men are segregated from the women. Dr. Hanssen is to be congratulated as an administrator for his low cost, paper and pencil solutions to the problems of handicapped mental patients.

One more suggestion which might improve treatment conditions is the appointment of a psychiatrist as director of each ward, instead of the senior attendant, who is the only representative of management on the ward. Many professional staff have been hired, but the attendants are in charge and regularly refuse to cooperate with professionals in the development and execution of patients' programs.

Which brings me to my purpose in writing to you. Carl Hanssen fired me three days after Sacramento investigated the allegations about the deaf and told him he did not have an adequate program. OCR did an adequate investigation on the deaf complaint; they aided the hospital administration in sweeping the rest of the complaints under the rug. OCR also refused to investigate my "protected activities" complaint, taking the Personnel Board's word for it that cause existed. An adequate investigation might have included interviewing myself or my lawyer concerning the basis of the complaint, or a review of the evidence systematically excluded from Ms. Davenport's opinion. OCR appears as a miscreant agency which audits the paperwork of bureaucrats rather than one which investigates complaints, especially when the offender is a state government agency.

Dr. Hanssen expedited my removal with the assistance of ward staff in the recruitment of two of the seven deaf patients on the ward to make an accusation that I provided a $2.50 "sexually explicit" magazine to them. Magazines are not on the list of articles which neither staff nor patients are prohibited from possessing, but I was charged with "failure of good behavior," and dismissed from my position.

There haven't been any complaints since I was fired, the so called "chilling effect" that wrongful terminations have upon reporting violations. It is difficult to induce the administration to document its own malfeasance. In the exhibits submitted when I was fired, however, there were several indications of their intentions:

A note dated October 14, 1982 from Jesse Harvey to Carl Hanssen stated, "Dr. Fischer was told not to contact outside agencies without at least checking with the program director. In the face of this directive he has continued to contact outside agencies particularly in respect to the deaf project. He contacted the G.L.A.D. agency, among others in September 1982, or earlier. On Monday 10/11/82 a call was returned for Dr. Fischer (who was on day off, holiday) from the National Center for Law on the Deaf."

Dr. Hanssen writes on October 29, 1982, while explaining why he refused my yearly raise, "He has selected to work almost exclusively with a very small number of handicapped patients, (approximately 3-4) to the exclusion of the larger population on the unit despite continuing efforts by his team members to refer other patients to him...That he process all communication with outside agencies through normal organizational channels..."

A memo from Carl Hanssen to me dated November 1, 1982 in response to the filing of the 504 complaint which named the four deaf patients discriminated against states, "Recently you initiated a contact with an outside agency representing yourself as an advocate for a special patient group in the hospital. In the course of this communication you revealed the names of our patients without their "express" consent. You should know that this action is a direct violation of the Welfare and Instiitutions code, Section 5328. Since, however, in this instance your intent was a positive one —in behalf of the patients' welfare—I will not press for disciplinary action. Nevertheless, you are hereby put on notice that the violation of a patient's confidentiality, inadvertent or not, is a serious breach of the California Administrative Code as well as your own professional code of ethics. As a licensed, health service professional you must understand that in your role as a psychologist in state service you are a therapist only. You are not a patients' rights advocate. That is a formalized position staffed by persons whose primary duty is to follow up on complaints concerning the abridgement of patient's rights...within the organization there are formal channels for complaints and you do not have the right as an employee to be an independent advocate or negotiater with any agencies outside of the formal state/county health care system."

To be succinct, Dr. Carl Hanssen refused to to provide equal treatment to the handicapped and then ordered me not to reveal this to the proper authorities. Though he was my direct supervisor, he did not testify at the hearing. He made a speech to the ward staff 1-24-82 about the findings of the state Office of Civil Rights that there was no program for the deaf at the hospital. He spoke about proper channels to management being necessary to prevent such things from happening, and that the deaf project had become a political football. "It's the people who don't care who are making the trouble. This is little stuff, it only affects a few. It is low priority. It is the senators and legislators who have their own special interests. There is somebody who thinks he is the ward attorney...and staff should make their feelings clear about these issues...to people who are faulting the process. These are the political issues that make things fall apart, this is the adventitious use of program problems."

In a phone call I made approximately February 1, 1982 to Dr. Jesse Harvey, I was told that the staff had been ordered not to have conversations with me by Dr. Hanssen. This made it impossible to contact two physicians (Dr. Lyons, who had previously agreed to testify, and Dr. Tsai) who refused to return phone calls because of this gag order. A Mr. Otto Penalver also refused to inform a staff member who testified, Mona Spencer, of my calls to her. She has confirmed this. The personnel office also refused to honor the Hearing Officer's order to allow me to inspect documents in my file. The date of the alleged incident for which I was fired was the date that I was interviewed by investigators sent from Sacramento to investigate the 504 complaint concerning the deaf.

A letter given to me from my personnel file dated June 20, 1983 from Denise Bates, Personnel Officer, to Anne Pressman, Deputy Attorney General stated, "This is a case that has received wide publicity and involves a federal complaint involving lack of services to disabled patients. We would appreciate having the attorney assigned be able to spend a sufficient amount of preparation time on this case since it is a little out of the ordinary." The crux of the matter appears to be civil rights, not the hastily contrived story of corrupting patients with a vulgar magazine.

Please ask the Office of Civil Rights to investigate my termination, not simply check the paper work of an administrator. It also seems as though the manner in which the Office of Civil Rights is conducting business could benefit from some scrutiny from Congress.

Thank you.

Edward Fischer, Ph.D.

Senator Weicker. If I could at this point pose a couple of questions to you: You have a very unique situation, do you not, insofar as your commission?

Mr. Sundram. Yes.

Senator Weicker. Is there any other statement that has the equivalent of your commission?

Mr. Sundram. No.

Senator Weicker. You in effect are the ombudsman, if you will, or the inspector general—maybe that is a better term—on behalf of the patients.

Mr. Sundram. We do a lot of different functions, some of which are patient advocacy, some of which are just holding the system accountable to the electorate.

Senator Weicker. You are not accountable——

Mr. Sundram. Oh, yes, I am.

Senator Weicker. Well, you are not accountable to the Governor, are you?

Mr. Sundram. Yes, I am. I am appointed by the Governor, and I am accountable to the legislature. I have a term of office of 5 years, and annually I am accountable in the budget process. If I am doing a lousy job of running my agency, I will face the consequences in that process.

Senator Weicker. Do you feel in the matter of your appointment that you have the total independence in being able to pursue the stated legislative objectives of your commission?

Mr. Sundram. Yes. I have been fortunate in the two Governors that I have worked for, Governor Carey and now Governor Cuomo; they have been very supportive of this agency.

Senator Weicker. As I understand it, you have the power just to move in right away on an institution without any warning.

Mr. Sundram. That is right.

Senator Weicker. As a matter of fact, my staff referred to your investigators as a SWAT team; they have the ability to move into an institution immediately without any notice or alerting of the officials.

Mr. Sundram. It is very important when you are confronted with a report that something is going awry in an institution to be able to get there right away because the trail can get cold awfully quick.

Senator Weicker. I realize the State government is your affair, but you are obviously well versed in all aspects of Federal legislation also. Is there sufficient authority at the Federal level to do what you are doing at the State level?

Mr. Sundram. Is there authority? No, I would guess there is not the kind of clear authority. If you are referring to the Civil Rights of Institutionalized Persons Act, there is a lot of bureaucratic rigmarole in that act that I would prefer not to see.

But I also think that the problem of trying to deal with abuse after the fact is really putting our energy in the wrong part of the problem. My feeling is that no matter how well we investigate complaints of abuse, we are always coming in after the fact. And the deterrent effect of the enforcement of law in this kind of a society in my mind is a fairly questionable phenomenon. I think we really have to be thinking about what can we do to prevent the kind of environments in which abuse occurs in the first place because it is really not much consolation to a patient who has been the subject of some flagrant indignity that somebody came along 6 months later and maybe finds the person who committed the act of abuse against them. I think we have to be thinking of what do we do to protect the people who are in these institutions because, after all, that is the source of Government's power. The Government took custody of these people in its role of protector of people who could not take care of themselves because that is the legal theory.

We have to find a way of discharging that responsibility a lot better. And from my view of the situation I think we have historically relied on institutions far too much, and I do not think we have the capacity under the circumstances that exist to protect people from abuse in large institutional settings such as exist everywhere in this country.

Senator **WEICKER**. Mr. Pharis, would you like to comment on this point?

Mr. **PHARIS**. Well, I agree very much with the description of the environment of institutions that Mr. Sundram gave and with the difficulty of investigating abuse and neglect and I think also just the occurrence of aggression between clients. Our accountability is somewhat different in that we are reporting to a Federal judge and we are reporting specifically around the issues of compliance in the lawsuit.

We do respond to individual case requests, but primarily in order to learn what we can about what it reflects about the implementation of the settlement agreement of the lawsuit. We try to refer clients to other advocacy groups for the kind of case advocacy that Mr. Sundram's agency provides. And there are limitations on resources in Texas for that.

Senator **WEICKER**. Do you feel that by virtue of Judge Sanders having appointed your commission, do you think that abuses, neglect, deficiencies, call it whatever you will, are being eliminated in the matter of the care of the mentally ill and mentally retarded in the State of Texas?

Mr. **PHARIS**. I think that there is a good deal of focus upon their occurrences, and I think there is effort at preventing and then dealing with them quickly. I think that they still occur. There are routine reports that we get from the Department on abuse and neglect, and it is still occurring. It is somewhat decreasing.

Senator **WEICKER**. How long are you going to be in being?

Mr. **PHARIS**. Right now we are authorized for one more year, April 1986. There have to be determinations at that point of whether there has been substantial compliance with the requirements.

Senator **WEICKER**. What worries me, and this is the reason I am also pleased to have Mr. Sundram's testimony, is that I know a lot of people are sitting back there in the institutions and they are a little nervous now about these hearings. I know what they are saying: it will all blow over. You fellows will blow over. He will not. He is in the statute there.

I have got to find the mechanisms now to make sure to the extent humanly possible that we can at least go ahead and discharge our trust as well as possible. Again, as we develop the hearings, I think people are going to find that in law right now those oversight capacities just are not there or whoever is supposed to be doing the oversight or whoever is supposed to be doing the accreditation or whoever is supposed to be doing the investigation, it is a self-serving process. We do not have the independence Mr. Sundram has. As he has indicated, he, as best he knows, is unique among the 50 States as far as State legislation is concerned. I think he probably is as best as I understand also.

Until you have that ability, it seems to me, of a totally independent look-see, the abuses will go on. And I must say I also agree with you that this problem is something to be caught before the abuse, not after; I could not agree more.

I wonder myself. I think any parent of a retarded child knows the tremendous amount of effort that has to go into that child, and you multiply that by a large patient population and I can see how these people who are supposedly doing the caring can burn out very fast, especially when there is inadequate staffing and untrained staff.

So I think any resolution of the problem lies, just as you have indicated, at that point in the spectrum rather than after the abuse has occurred.

Mr. **Sundram**. Yes. I would say that there are things that the States can be doing right now to improve the conditions under which care is delivered in their institutions, which includes making better efforts at recruitment and screening of prospective employees so that you do look at temperament and you do look at specialized qualifications where one would be willing to entrust the care of a dependent human being in the hands of the employee that you are hiring.

Senator **Weicker**. In New York State, what is the amount of vacation they get a year?

Mr. **Sundram**. It would depend on how long they have been in the civil service system. I believe you start with about 15 days a year and then you work your way up.

Senator **Weicker**. Is it the same for an attendant at a mental institution as it is for somebody working on the highways in New York State?

Mr. **Sundram**. If the grade level is the same, yes. There is no such thing as mental health days off, although the use of sick leave in mental institutions is higher than it is for the highway attendants. And I have always argued that is a good use of sick leave.

I would rather have somebody who feels the need to have a day off from work take it off than come to work and beat up somebody.

Senator **Weicker**. I would rather see a person have 3 months on and 3 months off, as far as I am concerned, because when they come back again they have the ability to do their best. I am just surprised that there is not some special provision made for these people.

Mr. **Sundram**. The problem, as I am sure you recognize, Senator, is one of money. The mental institutions in most States consume among the largest chunks of money in the State budgets, and there is always a question of how much the States are going to be willing to spend to run adequate institutions.

And that is why I think this issue or providing some incentives to the States to end their reliance on large institutions simply because they are a cheap and relatively efficient way of warehousing people—we have to provide some incentives to get away from that level of care. I do not mean to imply that community based services are perfect. They are not. Abuse can occur there as well.

But you have an awful lot of safeguards in the community that you do not have in institutions, the primary one being that the people are no longer isolated, that somebody else sees them every day, not just the caretaker. They go to a day program, they go to a work site, they are seen, and they have an opportunity to build relationships with other people where the fear of reporting will not exist anymore.

When you have different sites of residence and program you do not have as much a problem with the code of silence which exists in the sealed up society of an institution.

You are creating an environment where it is possible to report abuse and it is possible to do something because all the disincentives to reporting and to enforcement do not exist. And when you have those conditions then deterrence becomes real.

When an employee sees that if he does something bad to a patient it will be detected, discovered, and prosecuted, the chance that he will do it is probably sharply less. And our experience has been that we have noticed far less abuse in the community programs. And we run probably the largest number of community programs in the entire country. There is far less abuse in the community than there are in institutions.

Senator **Weicker**. I agree with everything you say except for one point, and that is the cheapness, if you will, of institutional care. It is most expensive, enormously expensive.

Mr. **Sundram**. It is expensive, but it is relatively cheap to run a bad institution as opposed to running a good institution. And I think if the choice is one of forcing the States to run institutions that are adequately staffed with adequate programs, and so on, they will discover that it is cheaper to place the programs in the community and to run decent, humane programs of a smaller scale in the community.

There are some tough problems of employment, and so on, that need to be dealt with, but they are not insurmountable. And I think what the Federal Government can do best here is to provide some incentives for the States to start following that path of conduct.

In the meantime I would encourage you to create some P and A's for the mentally ill. We really need them.

Senator **Weicker**. We fully intend to do that. They are something that fell between the cracks during the budget finagling, and they should not have. There should be P and A for the mentally ill, and I hope we can pass such legislation in this session of the Congress. That is relatively simple and straightforward: we should have the same advocacy for the mentally ill as we have for the mentally retarded. Maybe we have to improve both.

I thank you both for your testimony this morning. Your statements in their entirety will be placed in the record.

We will be recessing until tomorrow at 9:30 when we have further witnesses and further experiences to relate. But I would like to make the point today that the States of Texas and New Jersey and South Carolina and New York were highlighted; tomorrow Michigan, Georgia and Connecicut.

I think the point has to be made that all 50 States are in the same boat here. Nobody ought to be patting themselves on the back and saying there but for the grace of God go I. We are all in this together. Some might be making better efforts than others, but in terms of our regard for humanity, I am afraid nobody gets any gold stars in this area. It might be a best effort, but it still falls far short of the way we would expect to be treated ourselves.

The subcommittees will stand in recess until 9:30 tomorrow morning.

[Whereupon, at 1:21 p.m., the subcommittees were recessed to reconvene at 9:30 a.m., April 2, 1985.]

CARE OF INSTITUTIONALIZED MENTALLY DISABLED PERSONS

TUESDAY, APRIL 2, 1985

U.S. SENATE, SUBCOMMITTEE ON THE HANDICAPPED, COMMITTEE ON LABOR AND HUMAN RESOURCES, AND SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES, COMMITTEE ON APPROPRIATIONS,

Washington, DC.

The subcommittees met, pursuant to recess, at 9:30 a.m., in room SR-428A, Russell Senate Office Building, Senator Lowell Weicker, Jr. (chairman of the subcommittees) presiding.

Present: Senator Weicker.

OPENING STATEMENT OF SENATOR WEICKER

Senator WEICKER. Today we continue our hearings to examine conditions in State institutions. The response of the Nation's media on our first day is a testimony to the fact that these conditions are generally unknown to the American people, and they have provoked tremendous response across the land.

Now, two things. First of all, for any one desiring to communicate with the subcommittees of either Labor and Human Resources or Appropriations, I want to repeat the the numbers to call.

Given this opportunity to reach the Nation as a whole we are not going to lose it. It could very well be that, in addition to what is being presented to the committee, there are many others who have been forced into silence for too long. And I want them and I encourage them to take advantage of this opportunity to communicate with the committee.

All communications, I might add, will be kept in confidence unless the individual desires that the matter be public. The two telephone numbers that are involved: The Subcommittee on the Handicapped, the staff director is Jane West, and that telephone number is area code (202) 224-6265; the Appropriations Subcommittee on Labor, Health and Human Services, John Doyle, the staff director, is area code (202) 224-7283.

If anybody cares to communicate with the committee, they can call either of those individuals at those numbers or indeed anyone that answers at those numbers.

Point No. 2 is, Where does all this lead? I cannot emphasize enough my own fear of seeing these issues raised and then having nothing happen. That would be worse than no hearings at all.

I think it fair to assume, and here is the timetable I have set for myself and the committee, I think it fair to assume that we can accomplish the following two items this calendar year.

No. 1, put back into law the protection and advocacy and bill of rights for the mentally ill that was lost during the block grant legislation several years ago. That will be our No. 1 objective, to get advocacy and a bill of rights back into the law for the mentally ill. It presently exists for the mentally retarded, but not for the mentally ill.

Point No. 2, to so construct the certification process of these institutions that it does not become a self-serving operation, that is, the states certifying themselves, that is, the Joint Commission on Accreditation of Hospitals somehow being put in a position of either doing a better job than is presently being done or not doing it at all and having another entity accomplish that purpose.

Clearly as you will hear today, the accreditation process is not a process at all. These two items should be accomplished in the calendar year 1985.

A little bit more difficult because of the budget battle that we have would be some program that enhances the training of personnel at the institutions.

I am not certain in my own mind exactly how such legislation is going to be constructed, but clearly here we are talking about money, both in terms of training and the additional time off that has to be given the personnel that work in the institutions so that they do not suffer from burnout.

That is a possibility, but I do not feel as confident that can be done this year because of the wrangle going on in the budget.

Lastly, the one that I want to see put into place but admittedly will require substantial legislation, would be some form of an inspector general or a special prosecutor at the Federal level who would have much of the independence and the expertise as exhibited by Mr. Sundram and his committee in New York State. Something of that nature where there would be full legal powers at disposal to that individual and full access to the institutions of this country.

I think you can see by these proposals we are coming at the matter both before it reaches the stage of abuse, and also as an ongoing vehicle day after day rather than a subject of just occasional Senate/House hearings or investigations by the press or the State legislatures, so that there will be a consistent mechanism to assure that quality is being delivered, and care and compassion to our fellow first-class citizens who, by illness or, as I was properly corrected yesterday, by condition, find themselves in our trust and in our custody.

Our witnesses today come from Connecticut, Michigan, Georgia, and New York. The first panel consists of Vivian Mathis, advisor, Recipients Rights Office, Northville, MI; Richard Wellwood, president of Justice in Mental Health Organization, Inc., of East Lansing, MI; and Denise Colson of East Lansing, MI.

I express my pleasure to all of you and my thanks for the taking of your time and the giving of your effort to be with us here this morning.

Our first witness will be Vivian Mathis, and Ms. Mathis is here under subpoena. Would you please stand and raise your right hand?

Do you swear to tell the truth, the whole truth, and nothing but the truth so help you God?

Ms. MATHIS. I do.

Senator WEICKER. Vivian, you may proceed in any way you see fit, and it is a pleasure having you with us.

STATEMENT OF VIVIAN MATHIS, ADVISER, RECIPIENTS RIGHTS OFFICE, NORTHVILLE, MI

Ms. MATHIS. Thank you. Northville Regional Psychiatric Hospital is a facility for the mentally ill adults in Michigan. It houses approximately 1,000 patients and the recipients are ages 17 and above.

Basically at Northville we receive complaints from patients about things that affect their existence, not so much about abuse and negligect. Northville houses 1,000 plus patients. Forty percent of all MI patients admitted to the State of Michigan facilities are admitted to Northville; 300 patients are admitted to Northville approximately per month. The average length of stay for a patient at Northville is 80.6 days; 40 to 60 patients per night are slept off the ward due to overcrowding. Northville had 4,666 for the fiscal year October of 1983 to September of 1984.

An overcensus ward creates a number of problems for patients. Sleeping accommodations at Northville have been set up in visiting rooms and activity rooms. When a number of patients on a given ward exceeds the number of beds available, extra recipients have to leave their ward at bedtime. These individuals, along with their personal property and their linen, are bedded on another ward. Frequently patients are not slept on the same ward every night, and sometimes staff are unaware of the particular needs of that patient who is now sleeping off due to overcrowding.

The environmental issue at Northville is improving. However, one complaint that we consistently receive during the summer has to do with the heat. Recently we did a survey, an environmental survey at Northville which showed that at 9 o'clock temperatures outside in the morning were 72 degrees. Temperatures on the ward would be 80 to 85. At noon, temperatures on the ward were as high as 110 degrees.

The heat is unbearably high. The fans are basically inoperative or unavailable. The ventilation is poor. If you reside in a single-story structure instead of a tall building, frequently the temperatures on the ward is 15 to 20 degrees higher than the outside temperature.

So if your noon temperature during the summer is like 90, you are talking about maybe 110, 115 degrees on the ward. When you couple that with insufficient staff, staff now are responsible for taking the patients who no longer have ground cards out.

If you do not have sufficient staff, that means the patients are, therefore, left on the ward. So now you have no staff to take the patients out and you have a temperature of 110 degrees. There is no access to the ground without a grounds card, and if you have insufficient staff, you cannot even get to the yard.

This situation is being corrected. There is a plan to order ventilation systems for Northville. It is my understanding that fans have come in, and we are looking to the fans being installed by the summer. However, this condition has been in existence for a long period of time, and then when you couple that with the psychotropic medications that many of these patients are on, you are running a high risk of dehydration and other side effects.

In terms of the Rights Office at Northville, each rights adviser is responsible for approximately 200 patients. During the last fiscal year, October 1, 1983 to September of 1984, we received 10,366 incident reports. We received and reviewed 2,180 allegations of rights violations. We received 417 allegations involving abuse and neglect; 319 allegations of abuse and neglect were investigated during the last fiscal year. Approximately 512 complaints were investigated out of a total of 2,180 received.

And that is basically the situation at Northville in a capsule.

[The prepared statement of Ms. Mathis follows:]

TESTIMONY OF

VIVIAN E. MATHIS

RECIPIENT RIGHTS ADVISOR

MICHIGAN DEPARTMENT OF MENTAL HEALTH

ON

THE OFFICE OF RECIPIENT RIGHTS
AT
NORTHVILLE REGIONAL PSYCHIATRIC HOSPITAL
NORTHVILLE, MICHIGAN

PRESENTED TO:

LABOR AND HUMAN RESOURCES COMMITTEE

SUBCOMMITTEE ON THE HANDICAPPED

April 2, 1985

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INTRODUCTION

Act 258 of 1974, as amended, guarantees the rights of recipients of mental health services. This law assures rights protection for mentally ill and developmentally disabled recipients in Department of Mental Health facilities and their contract homes. This protection of rights is extended to all service recipients of community mental health agencies and to any provider who contracts with either the Department of Mental Health or community mental health.

Michigan's Mental Health Code did not vest the full responsibility for monitoring and safeguarding recipient rights in the hands of professional, administrative and direct care staff, but rather created the Office of Recipient Rights (ORR) in 1975 to carry out this function.

It is not possible to safeguard recipient rights by legislative mandate and or department directive alone. Changes in attitude and practices required by the enactment of such a code are not easily accomplished in this manner. Nor is it plausible to place the sole responsibility for this protection in the hands of the direct care, professional, and administrative staff of the facilities. Therefore, a rights protection system separate from the line of authority in the facility is necessary.

In addition, recipients are not always able to advocate for themselves. Placement in a treatment setting often makes them vulnerable to the whims of their caretakers. These recipients need assistance in understanding what their rights are, in knowing exactly how and when these rights may be limited, and in learning the procedures to follow in order to complain that their rights have been violated.

Currently, there are 24 facilities (and their contract homes) that comprise Michigan's public mental health system. Ten of these facilities serve the mentally ill adult, five serve the mentally ill child, seven serve the developmentally disabled, and two serve both recipients.

Michigan's Office of Recipient Rights has offices, staffed by at least one Rights Advisor, in each of these 24 facilities. Rights staff in these facilities answer to the Central Office of Recipient Rights, and are, therefore, independent of the facility's administration.

THE MODEL FOR MICHIGAN'S OFFICE OF RECIPIENT RIGHTS IS AN INTERNAL RIGHTS MECHANISM.

Rights service models can be divided into two groups: internal systems which are part of the mental health delivery system; and external systems which are administratively and fiscally dependent of the mental health delivery system. In a well developed rights system, both components are necessary.

Internal rights mechanisms operate complaint systems by:

-receiving, investigating, determining if violations exist and assuring that appropriate remedial action is provided for violations of rights;

-preventing violations of rights by visiting residential living areas, providing education and training to recipients and to staff;

-consulting with program staff on rights related issues, meeting with advisory councils, boards and human rights committees, assisting providers with drafting of policies and procedures and alerting the provider when agency practices violate rights; and

-monitoring various reports generated by the provider, the auditor general, licensing and accreditation bodies, for apparent violations such as abuse, neglect, serious physical injury and discrimination.

External mechanisms use advocacy strategies both inside and outside administrative channels and can be powerful in mobilizing external forces through direct contact with the legislature, governor, citizen groups and the courts. It uses negotiation and administrative procedures and is free to use litigation when other methods fail.

II. OVERVIEW OF NORTHVILLE REGIONAL PSYCHIATRIC HOSPITAL - THE RIGHTS SYSTEM

Northville Regional Psychiatric Hospital (NRPH) is a facility for the treatment of mentally ill adults. It currently houses over one thousand patients. The recipients in NRPH are aged 17 and over with diagnoses that span the range of mental illnesses. It houses both long and short term recipients in: admitting, long-term care, and pre-placement units with specialized programs for deaf persons, young adults, and forensic recipients.

The Department of Mental Health Office of Recipient Rights has assigned five staff to the Metro MI Unit. This unit provides rights services to NRPH as well as two other state facilities (4.4 full time employees are assigned to NRPH). Rights Advisors are assigned to buildings and each Rights Advisor is responsible for providing rights services to approximately 200 recipients.

NORTHVILLE REGIONAL PSYCHIATRIC HOSPITAL OFFICE OF RECIPIENT RIGHTS PERFORMED THE FOLLOWING RIGHTS ACTIVITIES IN FISCAL YEAR 1983 - 1984 (OCTOBER 1, 1983 - SEPTEMBER 30, 1984).

- Received and Reviewed 10,366 Incident Reports
- Received and Reviewed 2,180 Allegations of Rights Violations
- Received 417 Allegations Involving Abuse or Neglect
- Investigated 319 Allegations of Abuse and Neglect (not including Abuse III/Neglect III)
- Investigated 193 other rights complaints
- Investigated a total of 512 Rights Complaints

THE RIGHTS OFFICE AT NRPH DOES NOT INVESTIGATE ALL COMPLAINTS.

All complaints received are reviewed by a Rights Advisor. Due to the large volume of complaints, not all are investigated (1668 of the

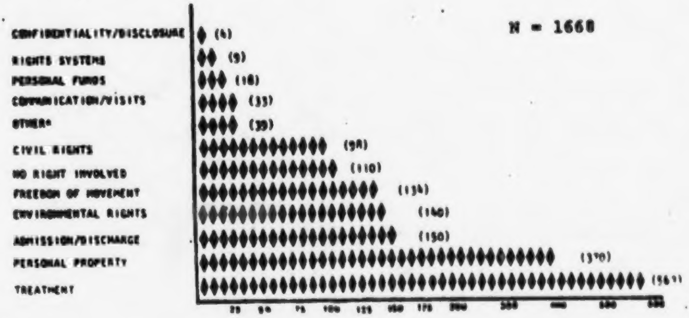
Fiscal Year 83/84 complaints fall into this category). The determination whether or not to investigate is made in accordance with the NRPH Office of Recipient Rights management plan which defines priorities. First priority for investigation are allegations of Abuse, Class I or II, Neglect, Class I or II (see definitions - Attachment B); all deaths of recipients; all serious injuries to recipients, and all allegations of discrimination. Second priority cases are issues relating to the environment and to treatment. These are investigated as time and work load permits. All other apparent violations of patient rights are investigated at the discretion of the assigned Rights Advisor. For those complaints not able to be investigated, the complainant receives a response which directs them to a facility staff member who will attempt to help them.

MOST COMPLAINTS RECEIVED ARE NOT IN REGARDS TO ABUSE OR NEGLECT BUT CONCERN ISSUES SURROUNDING TREATMENT.

Recipients complain most about things that affect their existence while hospitalized such as:

* having property stolen;
* confined to the ward without activities;
* refused access to the grounds;
* denied visit leave home;
* unable to have access to their psychiatrist for individual therapy;
* unable to have access to their social worker to discuss their problems.

Table A below indicates the number of non-abuse/neglect allegations received at NRPH by category for Fiscal Year 83-84.*



*See Attachment A for explanation of rights categories.

PATIENTS ARE CONCERNED ABOUT NRPH'S ENVIRONMENT

In the period of July and August, 1983, the Office of Recipient Rights received forty complaints regarding environmental issues. The rights office conducted an environmental survey August 11 - 18, 1983. In general the following conditions were found:

- wards with inoperative sinks, toilets and showers
- high temperatures on the wards (above 95° before 10:00 a.m.)
- many wards with insufficient amounts of towels, soap, washcloths, etc.

In October, 1983 a follow-up survey was conducted. In addition to the previous problems cited (most of which were still unresolved) the following concerns were added:

- insufficient amounts of furniture in living areas
- no storage areas for recipients' personal belongings
- inoperative drinking fountains
- insufficient amount of clothing available for indigent recipients.

At this time, the administration of NRPH has resolved many of the problems cited in the environmental complaint. Based upon the recommendations made in the report, the Michigan Department of Mental Health has sought and received the additional appropriations to remediate some of these concerns.

III. SPECIFIC RIGHTS ISSUES

A. TREATMENT

The primary mode of treatment at NRPH is that of medication. Psychotropics are prescribed to the majority of recipients. However there often is a lack of documentation regarding the rational for the medication prescribed. Medications are given to recipients by direct care staff. The recipient is not always provided with adequate information regarding medications and their possible side effects in order to give informed consent to treatment.

The second most prevalent method of treatment is the use of the seclusion/quiet room. Indications are that this technique is often used without the benefit of preventative counseling prior to the act of seclusion. Staff often use this type of intervention to get recipients to stop annoying them or for staff convenience rather than as part of an overall objective to reduce unacceptable behavior.

There is little documentation which would indicate that any of the recognized therapies (individual or group psychotherapy, millieu therapy) are implemented on a regular basis. Recreational therapy, occupational therapy and socialization programs are minimal in the most part due to lack of staff.

Individual treatment plans are not specific enough to provide staff with clear consistent guidelines for treatment of the recipients. They are not updated to reflect progress nor changed when a prescribed means of treatment appears ineffective.

Para-professional staff lack training in dealing effectively with recipients when they become agitated and require "talking down." This leads to uncalled for physical confrontations ultimately leading to the unnecessary use of restraint and seclusion. Staff are frequently found in the nursing station not interacting with recipients.

Special treatment issues concern recipients who either have a diagnoses of mental retardation or are admitted forensic patients. A review of clinical records showed that some recipients at NRPH are diagnosed as developmentally disabled. Their admission to NRPH was inappropriate. NRPH admitted these recipients due to the non-availability of appropriate beds in Wayne County. It is questionable whether suitable treatment is being provided. The facility has one forensic ward which is for male recipients. The female forensic recipients are scattered throughout the 11 female wards. Only one psychiatrist is assigned to forensic recipients. Female forensic recipients are not seen on a regular scheduled basis by the treating psychiatrist. Staff report that medications are renewed without the doctor seeing the recipients.

B. OVERCROWDING

An over-census ward is the precipitant of many problems for recipients. While on their home ward during waking hours, overcrowded conditions create a lack of space for adequate activities and for dining. On some wards activity/dining rooms have been converted to sleeping areas to accommodate additional patients. The crowded conditions can also be directly related to some of the increase in physical confrontations between recipients.

During night time hours when the number of recipients on a given ward exceeds the number of beds available, the extra recipients have to leave their home ward at bedtime. These individuals, along with their linen, are bedded on a ward possessing vacancies. In some instances, temporary sleeping accommodations have been set up in other areas of the hospital such as the gym and visiting rooms. Mentally ill recipients need a very structured environment and the constant movement from bed to bed or ward to ward, destroys any continuity for them. They find themselves in unfamiliar surroundings and the staff are not aware of their particular needs. Moving them in this manner also denies them the right to have a safe place for personal belongings.

Although the problem is directly related to the hospital's inability to limit admissions, it is perpetuated by procedures used when admitting patients. New admissions are not limited to those wards which are under census. Admissions rotate and wards over census receive a new admission if it is their turn, which exacerbates the problems.

C. ENVIRONMENT

Insufficient numbers of staff and outdated equipment make it impossible to keep both the on and off ward areas clean. Lack of furniture makes the wards look barren and detracts from the therapeutic environment.

The physical design of the buildings contributes to the retention of heat in the summer with temperatures on the wards reaching the 95-100 degree mark. Poor ventilation on the wards compounds the problem and also contributes year round to wards where the halls are clouded with cigarette smoke (no special provisions are made for those who are non-smokers or allergic to smoke).

The windows in some of the wards only open a few inches. There are wall and floor fans on some of the units but for the most part, the fans are ineffective in the cooling out and ventilation process.

Many areas of NRPH lack access to those in wheelchairs and with other handicaps. The geriatric and medical wards are not on the ground floor; evacuating the non-ambulatory patients during an emergency when the elevators are not working would be impossible.

A rights office investigation into limited recipient access to bedroom areas found a hospital wide policy prohibiting bed rest for 1½ hours after meals, and a requirement that dorms could not be opened unless there are at least three direct care staff on duty. Thus, the access to bedrooms is limited.

D. UNDERSTAFFING

Several wards lack a sufficient number of direct care staff with which to provide an effective treatment regimen. Although the number of staff on paper may approach standard recommended amounts that figure is reduced by sick and annual leave, often to where only two-three staff are responsible for 40-50 recipients. The number of professional staff is also not adequate to provide individualized treatment to the recipients. Four psychologists are available for all 1000 recipients in the facilitv. Recreational and occupational therapy staff are not sufficient to provide recipients with recommended treatment. Psychiatrists are assigned

40-50 patients and do not have adequate time to provide psychotherapy. Nurses often are responsible for several wards (especially on the afternoon and midnight shifts) and have administrative functions in addition to nursing responsibilities.

E. ABUSE AND NEGLECT

During the period May 1984 to October 1984, 147 complaints were received which contained allegations involving either Abuse I or Abuse II or Neglect I or Neglect II. This total comprised 13½% of the total allegations received by the NRPH Office of Recipient Rights during this period. Of these, 10 complaints were classified as Abuse, Class I, 127 as Abuse II, 3 as Neglect I, 7 as Neglect II (the definitions of Abuse and Neglect are contained in Attachment B).

Substantiation of allegations of Abuse or Neglect is based on a standard of the preponderance of evidence. This is often a difficult standard to meet. The investigative process is often hindered by the difficulty of identifying the person, or persons, responsible for the violation and in establishing the credibility of the patient involved or of those who may have witnessed the incident.

The Office of Recipient Rights data indicates that 53% of the allegations received were directed against staff working the afternoon shift. Indicative of the fact that 1) there is less professional supervision of the staff at this time, 2) during this time all recipients are restricted to the ward and the overcrowded conditions exacerbates the problem, and 3) that the overcrowded conditions of the hospital force the staff during this shift to move patients off wards to converted sleeping areas.

F. PERSONAL PROPERTY

Disregard for recipients' personal property is widespread. Documentation and procedures for disposition of personal belongings are lacking, which leads to a means of denying that the property was actually lost and therefore reimbursable by the facility. There are numerous complaints of lost glasses, dentures, hearing aids, etc.

G. SNACK BAR

The patient snack bar is housed in a small area and serves all of the 1000+ patients of NRPH who have grounds access. The area cannot possibly serve the recipients effectively. A lack of ventilation causes the room and the surrounding corridor to be continually smoke filled. Recipients from the outbuildings must walk a considerable distance when able to get off their wards; a lack of supervision creates the risk for recipients to injure each other.

H. PRE-PLACEMENT PROGRAMS

These programs are housed on three wards (two male, one female). Individual recipients assigned to these wards are technically ready for placement. These units have an open door concept, allowing

allowing recipients to fully exercise their ground card privileges and giving each person certain assigned responsibilities. The three pre-placement units have capacity of 139 recipients and currently house 129 recipients.

One of these is a recently opened ward which houses pre-Fairweather Lodge Program, a specialized concept which relies on the development of a reference group among the members which provides them with norms to follow and most importantly with peer social support. The program creates a social environment among its members of mutual responsibility for one anothers welfare.

Very few allegations of Abuse and Neglect are filed by recipients in the units. Their major concern is placement. Unfortunately, there are too few community placement homes for mentally ill adults to accommodate this population, and their hospital stay is thereby lengthened.

Another problem affecting pre-placement patients is one of limited recreational activities. The Activity Therapy Department at NRPH schedules a variety of on- and off-ground activities, but a lack of staff limits both the amount and variety. The pre-placement recipients, those in the NRPH population who could most benefit by this kind of program, receive only a minimal level.

IV. SUMMARY

Many of the issues addressed herein were also cited as concerns by the Justice Department in a report issued on February 19, 1985 based on their 1984 investigation.

The Department of Mental Health has attempted to respond to the concerns raised by both the Office of Recipient Rights and the Justice Department. Several steps toward remediation have already been taken:

-Replaced the former Facility Director with Dr. Walter Brown, who transferred to NRPH from his former position as Director, Bureau of Adult and Children's Psychiatric Services. His background also includes being Director of Michigan's largest Community Mental Health Board and this provides NRPH with an administrator who has a wide range of mental health experience.

-Authorized increased staffing in both the direct care and ancillary services areas. This has resulted in increased supervision of recipients and a healthier, cleaner environment for them.

-Sought, and received, a $14 million supplemental appropriation from the Michigan Legislature in order to begin to correct physical plant inadequacies and reduce the census through provision of additional community placement and private psychiatric beds.

-Began working with the local Community Mental Health Board to provide intensive pre-admission case management programs to deflect unwarranted admissions.

-Set a goal of eliminating admission of persons over 65 years of age by creating specialized geriatric pre-admission screening, treatment and discharge programs.

Finally, I am concerned that policies of the Health Care Financing Administration aimed at cutting funding of community programs in Michigan will result in further overcrowding of MI hospitals and an increase in the rate of recividism.

ATTACHMENT A

CATEGORIZATION OF RECIPIENT RIGHTS:

1. ABUSE

2. ADMISSION AND DISCHARGE

1) Chemotherapy
2) Discharge
  a) Formal voluntary
  b) Informal voluntary
  c) Involuntary
  d) Administrative
  e) Judicial
3) Hearings
4) Medical exam, independent
5) Objection
  a) To hospitalization (MI)
  b) To admission (DD)
  c) To placement
  d) To transfer
6) Pre-admission rights
  a) Informal voluntary
  b) Formal voluntary
  c) Medical certification
  d) Petition
  e) Geriatric
  f) Temporary and administrative
  g) Judicial

3. CIVIL RIGHTS

1) Abortion
2) Addressing a resident
3) Barrier free design
4) Business and personal affairs
5) Competency
6) Contraception
7) Dignity
8) Discrimination
9) Driver's License
10) Education
11) Labor and compensation
12) Marriage and Divorce
13) Media
14) Personal search
15) Privacy
16) Relgiion
17) Sexuality
18) Sterlization
19) Voting

4. COMMUNICATION AND VISITS

    1) Attorney/legal matters
    2) Funds for stationery, postage and telephone
    3) Mail
    4) Telephone
    5) Visits

5. CONFIDENTIALITY AND DISCLOSURE

    1) What is confidential
        a) Exams
        b) Fingerprinting
        c) Identification
        d) Interviews
        e) Other than record
        f) Photographing
        g) Record copies
        h) Substance abuse
        i) Tests
        j) Tours
    2) Appropriate disclosure
        a) Mandatory
        b) With consent
        c) Discretionary
    3) Privileged communication

6. ENVIRONMENTAL RIGHTS

    1) Clothing
    2) Diet
    3) Exercise
    4) Handicapped
    5) Humane
    6) Hygiene
    7) Provider premises
    8) Safety
    9) Sanitary

7. FREEDOM OF MOVEMENT

    1) Buildings and grounds
    2) General restrictions
    3) Individual limitations
    4) Least restrictive alternatives
    5) Leave of absence
    6) Restraint
    7) Seclusion

8. MONEY

    1) Dissipation of assets
    2) Easy access
    3) Facility account
    4) Limitations
    5) Safekeeping
    6) Use of funds

9. NEGLECT

10. PERSONAL PROPERTY

    1) Exclusion
    2) Limitations
    3) Protection when secluded or restrained
    4) Purchase or receive goods
    5) Receipt for
    6) Storage
    7) Theft, loss, or destruction

11. RIGHTS PROTECTION SYSTEM

    1) Complaint forms
    2) Explanation of rights
    3) Notification of rights
    4) Rights advisor

12. TREATMENT RIGHTS

    1) Case records
    2) Changes in type of treatment
    3) Clinical status and progress
    4) Examination, physical, social, and mental
    5) Informed consent for treatment
    6) Medical care
    7) Medication
    8) Periodic review
    9) Placement notification
    10) Private physician
    11) Research or "at risk" procedures
    12) Service, written plan of
    13) Services suited to condition
    14) Staff (stds/inservice/orientation)
    15) Surgery/convulsions/coma
    16) Treatment by spiritual means
    17) Unusual medical procedures

13. OTHER

    1) Facility standards reports
    2) Forensic provisions
    3) Guardianship
    4) Rights outside providers jurisdiction

14. NO RIGHTS INVOLVED

DEFINITIONS

ABUSE	I	An intentional act, or provocation of another to act, by an employee, contract employee, or volunteer which contributes to the serious physical injury or sexual abuse of a resident.
	II	An intentional act, or provocation of another to act, by an employee, contract employee, or volunteer which causes non-serious physical injury to a recipient or the unreasonable use of force by an employee, contract employee, or volunteer against a recipient with or without apparent injury.
	III	Use of language or other means of communication, by an employee, contract employee, or volunteer, to degrade or threaten a recipient.
NEGLECT	I	An intentional act or omission by employees, contract employees, or volunteers which denies the standard of care or treatment due a recipient as required by law, rules, policies, guidelines, written directives, or individual plan of service which contributes to the serious physical injury of a recipient.
	II	An intentional act or omission by employees, contract employees, or volunteers which denies the standard of care or treatment due a recipient as required by law, rules, policies, guidelines, written directives, or individual plan of service, which contributes to the non-serious physical injury of a recipient.
	III	An intentional act or omission by employees, contract employees, or volunteers which denies the standard of care of treatment due a recipient as required by laws, rules, policies, guidelines, written directives, or individual plan of service which places a recipient(s) at risk of serious or non-serious physical injury.

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Senator **Weicker**. Just a few questions. I understand your office is not able to fully investigate all claims of abuse and neglect received at Northville. Would you describe the kinds of abuse and neglect allegations that your office does investigate and the allegations that you are not able to pursue?

Ms. **Mathis**. Generally, we are required at Northville to investigate abuse allegations involving serious injury, nonserious injury or unreasonable use of force by staff. One thing you have to remember when you talk about abuse in terms of the State of Michigan is that every time you substantiate a case of abuse in the State of Michigan, you are talking about employee to patient. OK.

If it is a patient to patient abusive kind of incident, it is considered a treatment violation. It is not considered an abuse. So for our definitions, anytime we talk about abuse and neglect we are talking about employee to patient, and we must investigate all serious injuries and deaths, all nonserious injuries which would be like severe bruising, that kind of stuff, and also unreasonable use of force, and neglect. Similarly all injuries which could have sustained a serious injury or a nonserious injury.

What we do not have to investigate in terms of abuse and neglect at Northville are abusive situations vis-a-vis degrading, humiliation, communication, that kind of stuff, and also we do not have to investigate anything neglect-free which places the patient at risk of a serious injury. Those are optionally opened for us.

Senator **Weicker**. All right. Neither do you investigate, I gather, patient to patient?

Ms. **Mathis**. Patient to patient we do not investigate.

Senator **Weicker**. That is not investigated?

Ms. **Mathis**. No.

Senator **Weicker**. And the other matters that you indicated. Let me ask you a question only because I saw somebody make a comment last night when I was watching the reports on this hearing.

An official of one of our States indicated that they had not received any reports of abuse in the course of the whole year. I thought that was a rather interesting statement, but I also have done a little backgrounding myself and realize how hard it is to get any reports of abuse unless somebody is willing to stand up and testify, and have an employee testify on another employee. I mean, who is going to make these reports and how are they handled?

Unless you are really familiar with the jargon of your business one would assume that all allegations would come to your attention. Clearly there is a huge category of allegations of abuse and neglect that you do not have any authority over at all, am I correct?

Ms. **Mathis**. There are allegations of abuse and neglect that we have no authority over, but in the event that our office discovers that an abusive situation occurred that was not reported, then that person is disciplined, that is, a case is opened on that.

Every employee who has knowledge of an abuse or neglect situation must report it, and in the event they do not report it—they can individually report it or they can group report it by signing it at the bottom. Everyone has to sign. If your signature is missing, then many times we proceed on that failing to report abuse and neglect.

This is how we do it at Northville. OK. I do not know what happens at other facilities. I would assume that that may very well be true of other places, but at Northville, I have not really encountered very many situations where the abuse and neglect have not been reported. I just have not, and I have been there for about, well, this is the third year.

Senator WEICKER. You are strictly talking employee to patient?

Ms. MATHIS. Well, when patients attack other patients, incident reports are written. OK. We call them unusual incident reports. It is written for a variety of purposes. Every incident report that is written in the hospital comes to our office. We do not investigate patient to patient abuse. Patient to patient is considered a treatment violation by the Department of Mental Health in Michigan.

Sometimes we look into patient to patient under treatment. OK. If you have a particularly hostile and aggressive patient whose treatment is not being met for some reason, then we will look into that, because they are supposed to have a plan of service individualized to them. OK. And sometimes that issue may be missed.

So, yes, we do investigate some treatment issues, but it is not a priority for us.

Senator WEICKER. How many incidents that you have described as serious cases of abuse has your office investigated in the last 6 months?

Ms. MATHIS. We have substantiated maybe 10 allegations of abuse or neglect within the last 6 months. That is a substantiation rate. We have trouble substantiating cases.

Senator WEICKER. Now, you are getting to the point that I was trying to make earlier. Why do you have trouble substantiating cases?

Ms. MATHIS. Because of a variety of reasons, but one of the main ones is, as you indicated. We substantiate abuses and neglect on the basis of the preponderance of evidence. If we cannot say that we have established a preponderance of evidence, then we cannot substantiate it.

Frequently, what happens is that you may have an abuse situation with five or six patients as witnesses. What we do at Northville is we ask for credibility statements from the physician. We ask the physician "Is this a credible patient? Is he in tune with reality, space, time?," that kind of thing. We have a form. If the doctor signs the form and says, "This patient is credible," then we can use that patient as a witness and start establishing the preponderance of evidence.

That is the only way we can go, and that is why it is very few. Unless we can get a staff person that comes forth, which is rare, we have to go with the credible patients, and then what happens is that when that is grieved, OK, when that employees grieves that disciplinary action, frequently the patients are not accessible to come back. Then since we used those as witnesses, we have lost the case.

Senator WEICKER. The fact sheet on Northville Regional Psychiatric Hospital reads as follows. It is a nonaccredited Michigan State Hospital for the mentally ill. It receives no Federal funds, serves approximately 1,000 patients, 90 percent of whom are involuntarily committed.

The Department of Justice announced its intent to investigate Northville on November 15, 1982. Twenty-seven months later in November of 1984 the Department of Justice sent the Governor of Michigan a letter outlining the finding of its investigation.

These findings include: Staff deficiencies pervade all major disciplines at Northville. Severe deficiencies exist in all areas of pharmacology at Northville, and seclusion is widely used at Northville frequently without doctors' orders and sometimes without the involvement of any licensed medical personnel.

I would like to have you comment on that last one. Seclusion is widely used at Northville frequently without doctors' orders and sometimes without the involvement of any licensed medical personnel.

Have you received any complaints in that regard?

Ms. **Mathis**. Understand. Perhaps I should tell you this. When we get a complaint into the office, we read it. OK. We determine whether it is that priority. If it is not in that priority, many times we letter it to the facility and ask them to take care of it.

What you are speaking of is freedom of movement. Seclusion and restraint——

Senator **Weicker**. I am sorry. I did not follow you. You get a complaint and you ask the facility to take care of it?

Ms. **Mathis**. Because we do not have enough staff. If it is outside our priority, frequently we will letter it back to the facility for the facility to respond to the patient.

Senator **Weicker**. So the institution that is being complained against is the one that is going to investigate the complaint.

Ms. **Mathis**. For the most part.

Senator **Weicker**. For the most part.

Ms. **Mathis**. Yes, unless there is a situation where it has class implications or it is in our priorities, generally we do not look into it. What you are talking about in terms of seclusion and restraint, we would put that under either treatment or possibly freedom of movement. OK. We would not look into that.

Senator **Weicker**. You could not look at either restraint or seclusion?

Ms. **Mathis**. We could look at it. We can open it up, but it is an optionally opened case. It is not a priority. You see, we get maybe 200 complaints a month at Northville. OK. We have five rights advisers, two of them are part time. I have three full-time rights advisers at Northville for over 1,000 patients, really.

OK. Abuse and neglect take priority. Abuse one and two, serious, nonserious, unreasonable use of force are our priorities, and that is where we focus them. Out of 200 complaints, we may get 50 a month that allege abuse and neglect, and those are where we go to investigate.

A complaint that a patient would write regarding being secluded inappropriately, we may not look into at all because we are off looking at abuse and neglect.

Senator **Weicker**. Are unauthorized restraints, and unauthorized seclusion, considered abuse?

Ms. **Mathis**. No.

Senator **Weicker**. They are not?

Ms. Mathis. No. Unauthorized restraint is considered freedom of movement or treatment. It is not abuse by the definition of the department.

Senator Weicker. By whose definition?

Ms. Mathis. The department's definition.

Senator Weicker. By the Department of Mental Health of the State of Michigan?

Ms. Mathis. Yes.

Senator Weicker. Vivian, do you feel restricted in terms of legal authority and in terms of staff, as far as being able to accomplish what you feel is your job?

Ms. Mathis. Yes, I feel it is restricting. The reason I feel it is restricting is because if you look in this written statement you will see that on page 6 the number of treatment allegations we receive by comparison to the number of anything else we receive is far greater.

We have 563 treatment allegations in one fiscal year.

Senator Weicker. I am sorry. Could you run through that again? You have 563 what?

Ms. Mathis. Treatment allegations. Those represent the allegations—this is what we get most. These are the allegations, nonabuse and neglect that we receive most.

Senator Weicker. Nonabuse and neglect by definition of the department of mental health?

Ms. Mathis. Right.

Senator Weicker. 563. How many of those can you investigate?

Ms. Mathis. I do not have the breakdown for how many we investigated, but it is really very few generally.

Senator Weicker. It is very few. And you are in place in the State of Michigan—I am not talking about you individually now, but your office is there ostensively to assure the rights of the patients, is that correct?

Ms. Mathis. Right.

Senator Weicker. Northville, as I understand it, has no upper limit on the number of patients it can admit, is that correct?

Ms. Mathis. As far as I know, it does not.

Senator Weicker. Is overcrowding one of their problems?

Ms. Mathis. Yes.

Senator Weicker. Do you feel that contributes to the violent incidents that have occurred on the wards at Northville?

Ms. Mathis. I think there is a lot of things that contribute to incidents of violence that occur on the ward at Northville, but I think the lack of activity is one of the big issues. We do not have enough recreational therapy staff, OT staff. You do not have enough staff doing programming with the patients.

If you have 40, 45 patients on a ward and a lack of staff, a lack of scheduled activities, what are they going to do? When you speak of violence now, a lot of the violence generically, not in terms of the department that I see, is patient to patient, a lot of patients because they cannot and do not have activities scheduled.

Senator Weicker. That is the point I made earlier. You say a lot of that violence is patient to patient, but that is activity that you are not allowed to investigate.

Ms. Mathis. We can investigate it but it is optional. It is optional. We investigate some of it, but it is optional, because the priorities speak to abuse and neglect.

You asked me what do we investigate. We investigate abuse and neglect. The reason we have to investigate abuse and neglect is because of the seriousness and perhaps the possible legal implications of abuse and neglect employee to patient. OK.

We will investigate treatment. We have investigated treatment, but it is limited and it is optionally open because we receive so many abuse and neglect complaints per month. I cannot finish 1 month before we go to the next month.

Senator Weicker. You say because of the legal implications it is a priority item. What do you mean by that?

Ms. Mathis. Well, you have employees involved with patients.

Senator Weicker. You have the institution involved. You have the State involved.

Ms. Mathis. Right. You have quite a few relationships there, and I would think that any investigation that sustained an injury, any patient injury would be investigated so the Department would have some handle on the situation.

Senator Weicker. So in other words, you do not have enough time or personnel or statutory authority. Mind you, I am not referring to you as an individual. I am talking about your office.

Ms. Mathis. I understand.

Senator Weicker. The authority of your office. I want to help as much as we can. But one of the primary objectives, really is not the patient as much as it is to make sure that the institution and the State of Michigan, well, as the old expression is, CYA.

Ms. Mathis. Well, I would not say that, because I think generally the facilities in the State of Michigan and the department are concerned about remediating the situation. If that means that the employee is going to be disciplined, then that is generally done. I have not had problem of late with employees being disciplined.

Senator Weicker. Why do you say "of late"?

Ms. Mathis. Because there have been problems in the past, but now the department has put a new facility director in the facility, and different types of steps are being taken.

As of late, the cases that we have substantiated and requested remedial action for at Northville, the remedial action has been timely, appropriate and adequate. I would say maybe since December of last year. But before that, it was untimely.

Senator Weicker. But I gather in your testimony here that you are still not satisfied with the number of cases that come to your attention that you can actually handle.

Ms. Mathis. I guess what I am saying is that if I had my druthers, I think that it is most important to investigate the things that are most important to the patients, and I find those things to be seclusion, restraints, overmedication, treatment concerns, freedom of movement issues, admission and discharge.

We have a big problem with the attorneys in the State of Michigan and the court committing process.

Senator Weicker. But I find it hard to reconcile your list of priorities where you have restraints, seclusion, freedom of movement, et cetera, and yet these are only optional for investigation by your office, even though personally you think they are the most important.

Ms. MATHIS. I think that they are very important.

Senator WEICKER. Thank you very much. I might have some further questions.

Let me just proceed to our next witness. Richard Wellwood of Justice in Mental Health Organization of East Lansing, MI.

Richard, nice to have you.

STATEMENT OF RICHARD WELLWOOD, PRESIDENT, JUSTICE IN MENTAL HEALTH ORGANIZATION, INC., EAST LANSING, MI

Mr. WELLWOOD. Thank you.

My name is Richard Wellwood, and I am founder and director of the Justice in Mental Health Organization, Inc., a nonprofit, tax-exempt organization. JIMHO was founded in 1980.

Senator WEICKER. Can you pull that mike up a little bit closer to you?

Mr. WELLWOOD. Schizophrenics do not talk too loud, I guess. Maybe I need my dose of Thorazine, I am not sure, at this time.

JIMHO members are individuals who are having or who have had an emotional or mental crisis in our lives. Since the conception of JIMHO in 1980, we have become one of the most effective mental health consumer self-help/mutual support group, I believe, in the United States.

My learning process, because I am an ex-patient—I attempted suicide twice. I had a 2-week stay in a private hospital. I had a marvelous hotel room to live in. I was in a VA hospital for 2 months in Ann Arbor. I was treated as a human being.

In my rehabilitation process, I happened to receive a CETA position, and I wish we had CETA today to help my people get back into the employment field, but I worked at the Center for Handicapped Affairs in Lansing, MI, and I began advocating for vocational rehabilitation programs, actually when I started advocating, and also advocating for the rights of the mentally ill as part of the Handicapped for Civil Rights of Michigan, as there was none. That was back in 1980.

What happened since then is incredible, because I found out if you have not, you have not, and if you have no money, you have nothing. You are at the mercy of society.

I was very fortunate to get an education because I know more about mental illness. I know more about schizophrenic. I know more about psychotropic drugs than probably most psychiatrists, most social workers, because I have worked with over 700 to 800 of my friends, expatients or patients.

I have visited every institution in the State of Michigan, large ones. I have visited Ypsilanti 40 to 50 times—40 to 50 times—and the reason we went to Ypsilanti was to visit a friend of ours. Her name is Ann. Ann was a learning experience because Ann was in the county jail and the Michigan Institute for Mental Health in Ypsilanti and back to jail, to the forensic center and then to Ypsilanti.

After about 40 or 50 visits, we were escorted out of Ypsilanti by the security guard because they said we were coming there to help a patient escape—help a patient escape. What really happened was we would go down there every week and try to psyche ourselves up and make her happy, bring the community to her, bring her friends to her.

And because one time she was complaining about the tremendous side effects, the shaking and the quivering, and she complained about that she was frightened at night to go to bed, and they would put her in seclusion because she would not go to bed.

I did not tell her not to take her medication. I said talk to your doctor—talk to your doctor. The next time we came down, they said we could not see her any more. That is her civil rights.

And all I wanted to do was find out if we did anything wrong—if we did anything wrong—and I asked all the administrators could I see the doctor, and finally they set it up so that I could see the doctor.

There were four of us visiting that day. When we went in, they sent us back to the B-33, a locked ward, and I told them that the administrator had told us to come to see Dr. Diaz, and they put us in the visiting room on this locked ward.

The next thing I knew here comes four guards, and they said, "Out." And they told us that if we ever came back or stepped foot on that land, they would arrest us or any member of our group, and I could not believe what they were doing to us.

So I handed my card, Justice in Mental Health, which is gentle justice, and we did go back a week later and resolved it with Dr. Dawson, the head psychiatrist. He talked about bits and pieces. I called it paranoid.

When I was writing my statement here, my oral statement, and it is very difficult for me to write, I was thinking about that day, and the set me up. But from that point on, which thank God it happened, because what I saw there, I saw, at the time, and that is before the Justice Department went in, I saw something awful.

People laying in the lobbies. People having intercourse in the lobbies. A woman laying on the floor on the cement with the dress up above her head and gentleman or patient molesting her with no expression. You know, if they were enjoying it I would have walked on. So heavily drugged.

So I went to the State capital.

Senator WEICKER. Did you observe staff there?

Mr. WELLWOOD. No staff. I used to visit the ward. I could not even find staff. I could not even find staff, and I am person coming off the street. I am a person coming off the street. A have-not. One thousand patients. How can an individual be treated—an individual. These are individuals. I am an individual. And what worked for me will not work for somebody else.

So you have to have an individual treatment plan, and when you put 40 to 50 people in 1 ward, and the staff is sitting in their office locked in there or watching television, and I have a letter, and I want to read two things. Have or have-nots, and I could talk about this for hours, but I do not want to go beyond my 5 minutes. I am very fortunate to be here.

This letter was written to me on the 27th of March of this year. This young lady was released, I think, from Ypsilanti in January, in about that time. They say there has been an improvement at Ypsilanti which is not true, and I am going to read this.

It says, "Richard, the best of luck to you. I admire what you are doing. Hope this will help." I hope this will help some other woman. I hope it helps her if she ever has to go back.

"I was admitted to Ypsilanti State Hospital in October 1984 following 30 days at Mercy Wood." That is a fancy place, is it not? Money. Mercy Wood Hospital in Ann Arbor. "I was escorted in Ypsi State in a sheriff's car with my hands cuffed behind my back. Since I have led a very sheltered life, I have never experienced anything like this before. I felt like a criminal. It was a very degrading experience."

She has no insurance now. Where does she go? Ypsilanti, B-33. I was escorted off from B-33. She explains here the life in December 1984. That is recent.

> Life on Ward B-33 was a real experience. The staff were not helpful. They spent their time in the office, staff kitchen or watching television. I was terribly frightened of the other patients on the ward. I was threatened by a large woman who was eventually moved to the forensic center.

They are putting all these people in there together. No staff, no nothing. "I was hit by another patient who wanted a cigarette butt. Another patient who was disoriented hit me very hard in the neck." And we do not investigate those.

Safe environment we are talking about, are we not? That is in the mental health code. Safe environment. Safe from who? "Staff were not available to intervene. There was a lot of theft on the wards, and you had to be very conscious of your belongings. This was hard to do as staff would only let you use your locker at their convenience." Everything is their convenience and not ours. No wonder they say deinstitutionalization does not work because there is nothing there to work, and anything left is gone.

One other short thing about treatment. Mental illness. We treat people in these institutions. What is treatment? I still cannot believe that this is treatment. That is what is treatment.

"There was no therapy on the ward." What the heck is that place if there is no therapy. "I never saw my doctor." Where is all that information coming on his records, and how come he prescribes the medication if he has not examined that person himself?

"The social worker was new and so overloaded that it was very difficult to get a chance to talk to her. The staff did not engage in conversations with you. The only people you could talk to were your other patients who made very little sense most of the time." That is because they are so heavily drugged that they cannot make sense. "You felt very much like you were left there to vegetate.

This is a large institution. We can hear horror stories she begins to talk about her life. How can we say that these are even places to treat people? OK. Sometimes I get emotional because I see it every single day. I watch it in the paper. Deinstitutionalization is not working. How can deinstitutionalization not work if we do not even have a mechanism to see how effective Ypsilanti, Northville, or any other institution or even private are?

I have helped admit a person, but I make sure that person is in my local community where that person can call me any time if he has complaints about the medication because I will call the ORR. I will call the doctor.

And this lady here was so heavily drugged. The note here says, "I would have been drugged much more if my family had not continued to call the hospital, sometimes daily, and pleaded my case with the doctor and the social worker."

There must be an external advocacy. There must be groups of people like Justice In Mental Health. We are not radicals. We know what realism is.

Senator **Weicker**. Drugged in what way, Richard? Could you just expand on that? Drugged in what way?

Mr. **Wellwood**. Overdrugged.

Another issues. Now, we are going to go into medication and overdrugging because there is not proper diagnostic assessment. You have foreign doctors in most of the State-owned facilities. That is nothing against foreign doctors, but the language barrier is not there at all, and even in my local community, some of my people want me to go into their facility with them to talk to Dr. O or Dr. so-and-so or whatever to translate.

I am sitting there. This person is talking about one thing and the doctor is talking about another. Appropriate diagnostics. They just stick them on any old drug, and then a lot of times they are treating the side effects of the drug. They are not really being monitored.

Like I said, I have been very fortunate to work with my friends, 600 to 700, so they can stay in the community. I do not want them going to those institutions, and the worse thing is women. That is the worst.

The worst thing is the whole system. All the systems are not really helping us. Social security, general assistance. Even when they discharge us, all they do is put you on medication and say, "Here. Go back to the community." And there is nothing there. They already cut off the SSI. You cannot go back on to it until after you are discharged.

There is nothing in place. There is no concrete foundation. That is my job. That is my job. As I said, I have visited all the institutions.

We talk about recipient rights, and I respect all the people that work for recipient rights but they have no power. They have nothing. I received a call from a parent whose daughter was incarcerated at the State hospital in Newberry in the Upper Peninsula.

The daughter was abused by a staff person, physically abused, and needed medical treatment. The daughter was afraid to write a complaint because of the consequences, and the mother finally did it on her behalf.

The only result was a written reprimand, and you talk about terms, and this was an inappropriate term. He physically abused this person and he should have been fired on the spot.

But he had a letter of reprimand in his file. Is not that wonderful? And it said "inappropriate behavioral management procedures." Why do they not talk plain language and he beat that person.

Let us get the jargon out of there. "Inappropriate behavioral management procedure." Now, if we commit a criminal I am a rapist. I am a murderer; I am this; I am that, but when they do something, it is inappropriate behavioral management. Slap in their hands. It is like nothing. It is like nothing.

Recipient Rights of Michigan really cannot do anything. They developed it. It is all internal, you know, mental health professionals who were working in the mental health department which now is in ORR, policing their own people.

They cut their staff so drastically because it was part of the mental health budget so what do they cut first? OK. The watchdog.

Senator **WEICKER**. Mr. Wellwood, we will put your entire statement in the record.

[The prepared statement of Mr. Wellwood follows:]

TESTIMONY OF

RICHARD WELLWOOD

JUSTICE IN MENTAL HEALTH ORGANIZATION, INC.
2843 E. GRAND RIVER
EAST LANSING, MICHIGAN 48823

APRIL 2, 1985

before the
Subcommittee on the Handicapped

My name is Richard Weilund, Founder and Executive Director of Justice in Mental Health Organization, Inc., (JIMHO). JIMHO is a non-profit, tax-exempt organization founded in 1980. JIMHO members are individuals who are having, or have had, an emotional/mental crisis in our lives. Since the conception of JIMHO in March 1980, we have become one of the most effective Mental Health Consumer Self-Help/Mutual Support groups in the nation.

In the fall of 1980 my education began of what the public mental health system has to offer the "Have Nots", those who have no money or no medical coverage. Ann, one of the members of JIMHO, unfortunately suffered a relapse and what followed was incredible. We began to visit Ann at Michigan Institute of Mental Health, which was not too bad; at the county jail, where she deteriorated further; at the Forensic Center, where she continued to deteriorate; at Ypsilanti State Hospital, and then back into the community in Lansing. This is a period of approximately 18 months. We must have visited Ann 40 - 50 times during that period. What we observed on these many visits was overdrugging of Ann, unnecessary seclusion, a lack of activities during the day. On many occasions I would bring 2 or 3 of Ann's friends to visit her at Ypsilanti State Hospital. We would usually stay 2 - 3 hours. Our visits would include going to the hospital cafeteria where we would have something to eat, play the jukebox and dance, use our energies to bring Ann some happiness.

On those occasions when we visited Ann and the weather outside was bad, we would find numerous patients laying in the lobby of her building. On one occasion I observed about 20 patients laying in the lobby. I observed two patients, one male and one female, having intercourse against the wall. The female had no expression on her face. As I proceeded down the hall I observed two patients, one male and one female. The female was on the floor with her dress above her waist as the male patient continued to molest her. Again, no expression on the woman's face. The odor of urine filled the air. I became enraged at what I saw. I saw no staff, I saw the weak being preyed upon, I saw two females that were defenseless against their attachers because they were so overdrugged. .

When I become angry I speak out. I w[illegible] to state legislators, I went to the Director of Mental Health, I went to the Director of the Office of Recipient Rights (ORR), to advocate for improvements of care within these institutions. You see, when I am angry, I advocate but I do it in a gentle way. Because of my advocating, my speaking out about the conditions at Ypsilanti State Hospital; understaffed, overdrugging, no activities, I believe that it led to harrassment by that state institution. You see, each time we visited Ann and other patients, they would complain to us of the overdrugging, of severe side-effects from the drugs. We advised them to speak to their doctor.

On March 25, 1982, we attempted to visit Ann on a locked ward. The staff person who opened the door indicated that we could not visit Ann. Not because Ann did not want to see us, but, because "The Team" decided that after our previous visit Ann became agitated. The agitation that they were talking about was Ann asking them to reduce her medication because of the severe side-effects. You see, we never told Ann not to take her medication. Matter of fact; because she was fearful at night and couldn't sleep, Ann asked us to bring her some Sominex so she could sleep. We told her we could not bring her anything because we would get into trouble. Ann also indicated on many occasions that because of her fears at nighttime, if she refused to go to bed she was placed in seclusion. The previous week, before being escorted out on that beautiful day by such lovely, gentle (I wish) guards, Ann was again talking about her fears of going to bed. We tried to help her by telling her to think of us coming down next week, of the many friends in Lansing who love her. As tears rolled down my cheeks I couldn't understand how they could punish someone for being frightened.

Yes, we were escorted out of Ypsilanti State Hospital. It is believeable now but I couldn't believe it was happening at that time. Here we were, coming to the hospital; caring, loving, enjoying each other and then to be told that we could not see Ann anymore. We could not step on the hospital property anymore or we would be arrested. They, the hospital, had violated Ann's civil rights, and ours. On this occasion I had brought 3 individuals with me from Lansing to visit Ann. If I had known what was going to happen I would have come by myself because the 3 others did not deserve what took place.

I would like to share with you what I did to try to resolve the issue of not being able to see Ann anymore. When the staff person said we could not visit Ann anymore, we went to the Office of Recipients Rights to speak with the ORR representative. There was no one there. I knew a doctor at Ypsilanti State Hospital so I went to see him on his ward. He was not there. I then went to the administration buildign and the gentleman I was supposed to see was not there. Finally I saw a Mr. Skagg. I gently explained what had happened. I explained that we have worked with Ann over a two year period. I explained that we had brought Ann to my home for Christmas with my family, and to Lansing on many occasions. His response sounded as if he would resolve the problem. He said "give me five minutes to make some phone calls and I will get back to you." While waiting in his office I started singing a song to cheer myself up, titled "They are coming to take me away." I didn't know that they were planning to escort us out. Mr. Skagg returned and sounded really nice. He said Ann was unable to see us that day, but, if we would go over to Ann's ward we could talk with her doctor. We went back to her ward feeling that we had accomplished, that being, to find out what if anything we did to upset Ann. When we reached the locked ward, the buzzer was broken so we knocked on the door. The staff arrived and escorted us to the visiting room. In about a minute or two, through a little glass window I observed Ypsi guards. I thought they were bringing a patient to the ward. Then, the door opened and one of the guards said "Out!". One of my friends was wearing a suit and the guard kept looking at my friend probably thinking my friend was the leader of our group. I thought our friend had done something wrong. When the guard said "All of you - OUT", that was when I took charge. The guards escorted us out of the locked ward into the hall. I asked them "What did we do?" They told us they were told that we had come there that day to help one of the patients escape. I told them "That's crazy. We came here with love and kindness and this is what we get?". The guards then became hostile. One of the black guards hassled one of the individuals with me, a beautiful black lady. They asked us for identification and told us that they were escorting us off the property and that if we or any of our JIMHO members ever came back we would be arrested. I wasn't frightened because I knew that we had done nothing wrong. When we got to my car I handed the guards one of my business cards that says "Justice In Mental Health" and told them that we would get justice for this incident. A week later we met with the head psychiatrist, Dr. Dawson, of Ypsilanti State Hospital. At this meeting we were able to get the differences resolved.

What I found out at the meeting with Dr. Dawson was that the hospital had no idea of Ann's activities while she was on leave of absence. I knew more about Ann than the hospital staff did. What I found out was the hospital was/is more paranoid about what they were/are doing and people finding out about it than the patients who were labeled "Paranoid".

Because of what happened to Ann at the county jail and the state mental health hospital, I dedicated myself to helping others stay in the community, or, if needing hospitalization they would have an advocate in the community. Since that time I have assisted between 650 and 700 individuals who have been in various state mental health hospitals across the United States, in the State of Michigan, in Canada. Their stories are all the same. They have all experienced terror, overdrugging, abuse, and worst of all, rape. How can we continue to allow these large institutions to exist? How can we continue to allow co-ed wards? How can we continue to allow attendants to administer psychotropic or any other drugs? Each time I speak to an audience, as I am doing here, I look around the room and I see women. I think to myself what would happen if they were unfortunate and experienced a mental/emotional problem, had no money nor medical insurance, had to rely on society to help them, and the court ordered them to seek treatment in one of our state institutions. It is like the court is ordering them to be raped as a punishment for their mental/emotional problem. It is like the court is ordering them to their death.

What these large institutions do is make victims out of their patients, victims of society. The patients are punished for anything and everything that is natural to them. They are like people who have been held hostage. In the beginning of their incarceration they fight back. Then, because of the punishments they begin to cooperate. Towards the end of their incarceration they begin to like their captors, as did Patty Hearst. These people are broken. They are never prepared to re-enter society and the community.

I have visited five (5) of the largest mental health institutions in the State of Michigan; Kalamazoo Regional, Ypsilanti State, Clinton Valley Center, Traverse City, and Northville over the last 2 years. The only improvement that I have seen was at Ypsilanti after the Justice Department initiated their investigation into the conditions of Ypsilanti State Hospital. The building was much cleaner, no one was laying in the lobbies, most of the patients were locked up. I know for a fact that in the State of Michigan the improvements are slight. We are still warehousing our people. We are still understaffed. We are still overdrugging our people, and, these institutions are still unsafe.

As of December, 1984, when one of our young men was released from Ypsilanti, the conditions still exist there. I did not personally visit this young man during his incarceration but his father, who is a doctor, consulted with me on his sons' treatment. The father stated that his son was vegetating. This young man is 19 and had come from the adolescent ward to the adult system at the age of 18. What he got for needing help is NOTHING.

I continue to receive calls from across the state from individuals experiencing the inhumane conditions within our hospitals. Most recently an individual was petitioned to Northville State Hospital. While waiting for her hearing she was attacked in the bathroom and choked by a fellow patient. This is just another example of the court saying an individual needs help and placing them into a dangerous environment.

I received a call from a parent whose daughter was incarcerated at a state hospital in Newberry, in the Upper Penninsula of Michigan. While her daughter was incarcerated she was physically abused to the point of needing medical treatment. The daughter was afraid to write a complaint because of the consequences. The mother did sign a complaint with the ORR and the hospital of the physical abuse of her daughter. The results of that complaint was a letter of reprimand being put into the employment file of the staff person. The letter of reprimand stated "He used inappropriate behavorial management procedures." Inappropriate behavorial management procedures; the description of his act is like slapping someones hand, like it is nothing. He should have been fired immediately. He is unqualified to work with people with emotional/mental problems. In addition to what he had done to her in the hospital, because she lived across from the hospital, he threatened her each time they met. I personally could not persue her case because of her fear of him. This must stop! Anyone who works for the State of Michigan, belonging to a union or not, must lose their job immediately and have to stand trial in court for their acts, the same as any criminal.

What can I tell the parents? That their daughters will be well? That their daughters will recover from these attacks? That their daughters will be safe within the walls of our state mental health hospitals? That they will receive respect, kindness, the appropriate treatment? Maybe you will tell them for me of what lies ahead.

In conclusion, people with emotional/mental problems are individuals who have led supposedly normal, happy lives until this devastating mental/emotional crisis entered their lives. The emotional/mental pain is torture enough. They are human beings with a problem. We must do everything in our power to assist them in their recovery.

We must have more research into more humane medications, humane structured hospitals, humane settings within the community. We must set forth a check and balance system to monitor all hospitals who serve the "so-called" mentally ill, both private and public. In the State of Michigan we thought we had this check and balance mechanism. We had the Office of Recipients Rights, which is supposed to resolve complaints from patients about their rights. But, unfortunately, ORR is an internal mechanism with no authority and the ORR staff was cut so drastically that they can only investigate the most severe cases; murder, rape, etc. I want to state here that I believe the majority of staff at these hospitals are kind, decent people. But, they are overwhelmed by the understaffing. Being overworked and with the threat of being fired, losing their jobs, they will not speak out.

I respect the Director of Mental Health of the State of Michigan. I believe he has attempted to resolve the problems that exist within our state. Without the cooperation of the Federal and Stategovernments in providing appropriate funds and the appropriate check and balance mechanism, conditions will continue to deteriorate.

I want you to think about our young people, our children who might be emotionally/mentally impaired. When they reach the age of 18, what is in store for them? I want you to think of our society today and the stresses that we deal with each and every day. I want you to think of the chemicals that are being used today within our food and our environment and how it might react on our mental health. I have met hundreds of individuals who are suffering emotional/mental problems. Each time I meet one of them I see them as a human being with feelings, pain, confusion, and animosity towards the society because of what has happened to them. The loss of jobs, the loss of family and friends, the county jails, the mental institutions, the side effects from the psychotropic drugs, and, most of all, no one understands them. No one believes them. Yes, some do have delusions, hallucinations, and yes, some do hear voices. But, once they have experienced these things, no one believes them any more; it is all in your head. Believe me, when they talk about rape, being so overdrugged they can't stand up, when they talk about all that exists in the institutions is sitting smoking cigarettes, you can now believe them. You see, I have brought with me two reports from the United States Department of Justice on their investigations of Ypsilanti State Hospital and Northville Regional Hospital. Sadly, these reports have confirmed the inhumane conditions that we have advocated against for the last five years.

Thank You.

Walbrood

Senator **Weicker**. Mr. Wellwood, I wonder if I could ask you a question which I think gets to the most important part of your testimony. You have described intolerable situations at Ypsilanti Regional Psychiatric Hospital.

Mr. **Wellwood**. Yes, sir.

Senator **Weicker**. Did I understand that in 1984 Ypsilanti became accredited by the Joint Commission on Accreditation of Hospitals?

Mr. **Wellwood**. Yes, sir.

Senator **Weicker**. One of the monitors on which the Federal Government relies to insure that health and safety requirements are met. Yet this organization frequently allows a great number of deficiencies to exist in accredited psychiatric facilities, and unfortunately that is true of Ypsilanti.

I have here a copy of the July 1984 accreditation survey of Ypsilanti by the Joint Commission on Accreditation of Hospitals, conducted at the same time as the Justice investigation.

The JCAH report cites the hospital with a number of deficiencies including the following, and I quote:

> Metal chairs with trays fastened across the seat which were originally used to feed physically handicapped patients are now used for purposes of restraint. Additionally seclusion is overused by staff. There is a lack of documented staff training in the use of restraint and seclusion and methods of detecting drug side effects of toxic reactions have not been developed.

Now, I also have here a copy of the Justice Department's letter of findings to Ypsilanti, and the letter states, and I quote:

> The likelihood of harm suffered by patients is increased because of staffing deficiencies, questionable psychopharmacological practices, unjustified use of seclusion and restraint, and the absence of medically accepted psychiatric treatment programs necessary to avoid undue risk to personal safety and insure freedom from undue bodily restraint.
>
> Unless (and this is the Justice Department), substantial improvement is made in all of the areas focused on above, conditions at Ypsilanti will remain in violation of the U.S. Constitution.

Would you please tell me, or anybody tell me, how some hospital can be accredited by one organization while another organization says they are in violation of the Constitution of the United States?

Mr. **Wellwood**. I could not even understand what it meant—Accreditation. Just because I hire some more staff—psychiatrist, the doctor—not the care staff, what does it mean then? I am going to the same definition of treatment.

You are saying we treat people there, then it is accredited. We have staff. All it means is you have staff. It does not mean that they have changed their procedure. To take Federal dollars away which takes more staff away, OK, that is one of the things we do. If you are not accredited, we will not give you Federal dollars.

And the people, our people, my people are harmed worse. I do not know. There has got to be something done now.

Senator **Weicker**. Yes. Let me address that point that you make because I think both you and I agree. Why take the Federal dollars away? All that does is go ahead and hurt the patients.

Mr. **Wellwood**. That is right.

Senator **Weicker**. As far as I am concerned, what you ought to do is either establish, as was recommended yesterday, treble damages against either the personnel or the State and the institution itself. Let the State pay the tab.

Do not take it out on the patient. They are already abused enough without financial abuse. That is the last thing we need to go ahead to do.

Mr. **Wellwood**. For that facility to be accredited, there must be social programs, recreational programs, therapy, drug educational programs. So that person is actually rehabilitated or healthy when they leave, not just put there and medicated and vegetate.

Senator **Weicker**. Let me ask you one last question before we move to Denise. You alluded to the young lady who wrote you that letter as being put in the sheriff's car and handcuffed.

Mr. **Wellwood**. Yes.

Senator **Weicker**. I made a statement yesterday and I know a lot of people even on my own staff said, "Well, Senator, I do not think that way." And everybody throws up their hands, but I will stick to what I said. I think one of the problems that we are dealing with is that we do not look upon these people as being ill, that is suffering from cancer or from heart. We do look upon them as criminals, and I do not care how much America wants to deny it, believe me; our feelings tend toward that direction far more than the compassion which we show for people of an illness or of a condition.

And I wanted your comments, since you alluded to being handcuffed and being carted away, as to how you viewed it when you went through the experience.

Mr. **Wellwood**. Like I said, I have been very fortunate to have worked with my peers, 700 of them, and they are human beings. They are beautiful human beings.

Senator **Weicker**. They are first class citizens, and they have not been convicted of anything, have they?

Mr. **Wellwood**. No, most of them have not. A very small percentage, maybe, they are hallucinating or paranoid or whatever, or maybe they are in a restaurant and sitting for a long time or maybe they are doing a lot of things, but they are not dangerous to anyone.

It is really sad because even in my own community, I am the only one who does crisis intervention, going into somebody's home, and I am not afraid of any of them as my friends, but I am afraid of the average citizen in the street, because I know.

Somebody says how do you communicate to a mentally ill person. Well, you are looking at one. And how do you communicate to me? Hi, how are you? And you look at me as somebody nice and not a schizophrenic.

See, that is the sad mistake with mental health professionals. They are always treating the behavior and they forget about the person. Well, it is the same. I agree with you. I am not a cancer. It makes me sick when I ask my friends because I have to deinstitutionalize them. I say who are you, and one lady said, "I am a mental patient."

It is sad. I want to find that beautiful lady that was there one time and she needs to go on with life. I am very fortunate. I survived through all of that, and Denise is very fortunate. But she did it because she had special people working with her and not just any old body. People who loved and cared for her, and today she is working as I am, and we want to continue to work, and we want to continue to be productive, and we want the opportunity, but you do not have an opportunity if you are punished for natural behavior.

Thank you.

Senator **Weicker**. Why do we not use this as the time to hear from Denise Colson of East Lansing, who is former patient at Ypsilanti.

Denise, why do you not proceed with your testimony?

STATEMENT OF DENISE COLSON, EAST LANSING, MI

Ms. **Colson**. My name is Denise Colson. I live in Lansing, MI. I am here today to testify on the care and inhumane treatment that I received while I was at Ypsilanti State Hospital. Would you please bear with me while I share with you the horrifying things that happened to me? When I was there I was raped three times. Raped three times. I would like to describe to you what it is like to be overdrugged and raped.

The first two times I was raped was when I was admitted to a coed ward. I was so overdrugged that the men held me up with me half falling on them and raped me while I was standing on my feet. It was awful. I could not even fight back—I was that overdrugged. I just did not have the power.

The third time was even more terrifying. The man was known as Christ around the hospital, and most of the people believed that he was Christ. He said that he was taking me to be healed and took me to one of the empty corridors in the hospital and took off our clothes saying that we had to be in the light of the Lord. Then he had me lay on the floor and forced himself on me. He was drooling all over my face, and he said that he was going to do it to me until I was dead, and I screamed, and then he put his mouth over mine and just started to suck on my lips until my mouth was all black and blue.

When I went back on the ward, they could tell by my face that something had happened, and it was awful. Rape is frightening for anyone to have to go through. It still has scars on me. It scarred me emotionally and mentally. I still have a lot of flashbacks about it as a result.

My social worker, when she was told about the attack, she said, "Well, we better get you on birth control pills if things like this are going to happen."

As far as the staffing goes, there are not nearly enough workers to watch the patients. There are four on a shift at the most, and they were there to care for 50 patients. A lot of fights broke out. There were fights between patients over cigarettes, money, chewing gum, and candy bars.

When I was on B-33, I had a woman pull me down to the floor by my hair because I had refused to give her a cigarette. She was quite ill, and this woman used to dig in the toilets and get out the feces and she would throw it at other patients and staff and she would eat it and it was just gross.

The hospital atmosphere is so sickening. It is dirty and it smells like urine or cigarette butts all over the floor and patients just spit and urinated wherever they wanted and cockroaches were everywhere in the hospital. They ran everywhere. I could remember when I went in the bathroom and turned on the lights, they would scurry, and I would just scream.

In the summer months it got so hot on the ward with the urine smell, and we would just be covered with flies when we sat in the day room.

With the hospital understaffing, they got rid of most of the janitors, and the patients did the cleaning, and that is how we would earn our treats at night. They would give us a Pop Tart or some potato chips if we helped clean the ward up.

When the budget cuts took place, a lot of the janitors were the first to go, and it alarmed me because a lot of the time was spent talking with janitors. They would talk more to us than the psych techs would, and sometimes it was our only communication with sane people. The psych techs, a lot of times, said they were busy with paperwork, did not have the time to sit and talk with us. Most of the time they would sit in the office and just talk among themselves or tell jokes or talk about the other patients, and it is not true of all the techs. There were some there that helped me and I will remember them for a long time, but most of them just did not have the time to spend with us.

My mother—she was the one. She was very supportive and understanding, and I would probably still be there if she had not come. She came every weekend from Webberville to see me, and she would say, you know, she just hated the overdrugging. She could tell I was so overdrugged. She noticed it every time she came, and she said I would sit drooling, not uttering a word, with a blank expression on my face. She would ask me every time she saw me to talk to the doctor and have him reduce my medication, and I would ask the doctor every time I saw her, which was usually about once a month that I got to see my doctor, and she would just tell me that I needed the medication to get better.

It was awful staying at the hospital. We got up very early in the morning with nothing to look forward to but laying around all day and hoped that no one would fight with you during that day, and the main thing we looked forward to was what would be good for dessert for lunch.

I was put on the locked women's ward, and the girls would just pull the chairs together. They were soaked with urine. It smelled bad. And just lay around on those all day.

Something has to be done. There has to be some changes made, because it is awful to see humans being treated like animals.

Another thing that I would like to see changed are the co-ed wards. They are not safe for anyone. If one of you, if your wife or your daughter were admitted to one of these wards and had to go through what I have been through, you would see things a lot differently.

There was a retarded girl on our ward. She could not talk. She just made funny noises and one of the staff members asked her to get out of the hallway, and she did not move. I do not think she understood him, and he twisted her arm up behind her back and pushed her, and she pointed to her arms for 2 days before they did anything about it, and they took her over to the doctor there at the hospital and she had a broken arm and was not treated for 2 days.

I saw people being put in straitjackets and locked in seclusion for days at a time. In the seclusion rooms there are no toilets. There is just a mat on the floor and four cement walls.

My memories of seclusion are not pleasant but I did not have too many memories or too many times put in seclusion. There were a lot of people who had it much worse. Richard and I, we went to Ypsilanti during the winter. We had a friend who was in, and they had put him in seclusion. He started banging his head on the walls. So they took him out, and he started banging his head again so they put him right back in. He unconsciously grabbed onto this radiator. There was a steam radiator in the seclusion room and he had real bad second-degree burns all over his hand, and they did not even know that it had happened until the next morning.

But there has got to be some changes made. The seclusion, the violence, the rape, it is all crazy. Like we go to these hospitals for help, emotional and mental help, and we get even worse treatment. We just do not get the help we need, and I am just lucky that I made it out alive because there are some people that do not. There are deaths that go on there.

And knowing Richard and JIMHO, they have helped me quite a bit. With my friends' support, I have come a long way. There have to be some changes made.

Senator WEICKER. I think that you are a very wonderful and a very brave person.

Ms. COLSON. Thank you.

Senator WEICKER. Denise, what did you do after the rape? Was there an investigation? Did you make a complaint? In other words, what was the response, either the first or the second time?

Ms. COLSON. The first two rapes, I was too afraid to report it. I did not report either one of those, and the last one I did. And they had the police come in and talk to me, and they said the man would be put in the forensic center. They took away my ground privileges. They said he would be put in the forensic center, but what I read in the newspaper article was that they just restricted his ground privileges, too.

Senator WEICKER. So he was still free on the institution grounds to go after you or anybody else, is that correct?

Ms. COLSON. Yes.

Senator WEICKER. Vivian, is this the type of complaint that would come to your office?

Ms. MATHIS. Yes, definitely, that is the kind of complaint that does come to the Rights Office.

Senator WEICKER. Richard, in your experience with the complaint mechanism whether it was Denise's experience or the experience of the person with the broken arm that she attested to, or the second degree burns on the hand, is the mechanism adequate to take these situations into account? Or is it the wall of silence that we keep hearing about which is impossible for a patient to get over?

Mr. WELLWOOD. Well, it is a combination of things. First of all, it was a murder or somebody got killed, the complaint would rapidly go to the director of the department of mental health, and the director, as we know, is the ultimate authority over any complaint from the Office of Recipient Rights. It is an internal affair anyway.

Many of the people who file similar complaints or complaints, they do not even receive a response until maybe 2 months after they are out of the hospital. So again, with the staff being with one person covering 1,100 people you just pick and choose, and that is what she does, and she probably does the best she can do. But the rest just fall by the wayside.

I guess another issue here, and I do not mean to dwell on this is that is why people refuse treatment after they get out. They get out and they never want to go back. They do not want to go near mental health again.

Senator **Weicker**. Let me ask about the treatment. This is my last question in this area. Therapy, as you indicated, is what you are supposed to receive. Did you get any therapy? Obviously, you and Richard have developed a purpose in life here as you are helping a lot of people, not the least of which, at least as I sit here and talk to you, is helping yourselves.

Apparently you have accomplished something between the two of you and your friends that the institution was incapable of doing. That is why I have to ask the question. Did the institution do anything except to make matters worse, which was the physical testimony that we heard yesterday?

Ms. **Colson**. It is like we talked about earlier. It is just a holding tank. It is just a place you go where you are really ill to keep you out of society and keep you in with other mentally ill people.

As far as I am concerned, no, I did not receive any help there.

Senator **Weicker**. Richard?

Mr. **Wellwood**. I would just like to make one comment, and I will explain to you what it really means to our people, therapy, treatment. We have in our community a local hospital which has a big mental health, 30-day, 30-patient capacity through community mental health and also private and they are above each other, one unit A and unit B. Unit B is public mental health, and it is almost similar to, you know, they have some occupational therapy and that is about it. There might be some changes now, but on unit A, the private, they have all kinds of therapy, recreational therapy, a lot of activities and the patients on the public mental health ward will say, "Well, how come we cannot go up on the third floor and have group therapy? How come we cannot go have group therapy?"

For me to look at Ypsilanti, you know, the lady I was talking about, today she has been out 1 whole year and it was from the effort of Justice in Mental Health, her therapist in the community, her mother and we had a struggle for a whole year to deinstitutionalize her and today she is doing so well.

Everytime I see her smile, I am happy that I worked so hard, and we worked so hard to keep her out of the hospital. So when I look at treatment, I look at it in a human way, and I can remember yesterday, and I better quite, yesterday just before I got to leave a friend of mine was in my office and he said it would be nice if friendly people come and take us to friendly places.

Senator **Weicker**. One last question relative to your response, Vivian, in earlier testimony. You indicated to me that your office would not be involved in patient-to-patient abuse. So how would it get involved in the situation described by Denise?

Ms. **Mathis**. Well, she indicated in her situation that the State police were called in. Now, I cannot speak for Ypsilanti. If that situation occurred at Northville, anytime the State police are called in to investigate an allegation similar to hers, then we are called in also, and we sit there as a matter of course.

Senator **Weicker**. But as a matter of definition, it would not qualify?

Ms. **Mathis**. We do not look at it. No.

Senator **Weicker**. I want to thank all three of you. Your testimony has been given very eloquently, and again, I want to thank you for making the effort and for giving of your courage and your experience. I think you are going to help a lot of people.

The last panel to testify consists of Mary Tinsley, a Volunteer Advocate from Roswell, GA. Attorney Bruce Goldstein of Bouvier, O'Connor, Cegielski and Levine of Buffalo, NY. Elena Rose of Buffalo, NY. And Bonnie (Yvonne) Olenick of Middletown, CT.

Again, it is a pleasure to have all of you here, and why do we not proceed in the order announced. Mary, please testify as you deem fit.

STATEMENT OF MARY TINSLEY, VOLUNTEER ADVOCATE, ROSWELL, GA

Ms. **Tinsley**. Senator Weicker and members of the committee, it is a personal pleasure to appear before you today to speak on behalf of Joseph Griffith as a concerned citizen and advocate.

Joseph has a diagnosis of Autism and Mild to Moderate mental retardation. Autistic people, by their nature and sometimes rather bizzare behavior, are probably the least understood of all the institutionalized population and are, therefore, more likely to be abused than some of the others.

Because there are not many and in most cases not any appropriate community-based residential programs, families are left with two alternatives:

One, they could keep their children at home with little or no support either from the school system nor the medical field or,

Two, they could place their sons or daughters in a large State institution, and such was the case here.

Joseph was institutionalized at the age 12½, and as you can see from his picture, he looked like any other 12-year-old. Due to the extremely good support, hard work and love from his family he functioned at a near normal behavioral level, and I was told by his home teacher that at that point in his life he was ready to learn to read and write.

Suddenly Joseph's world fell apart. His father died. His mother became ill. She was unable to provide the structure and support he needed in the home, and the only alternative was an institutional placement.

Joseph is now 23 years old. The years of institutionalization have taken its toll on this young man. It has resulted in the systematic destruction of a human being, and his pictures can give you a clear picture of what happens to people like Joseph in these institutions.

This is Joseph today.

Senator **Weicker**. These pictures will be made available to others. I realize they are a little difficult to see on camera. This is the picture of Joseph at 12-years of age?

Ms. **Tinsley**. Yes. That is 12, and that is 23.

Senator **Weicker**. And these pictures here are Joseph at age 23. How many years in an institution?

Ms. **Tinsley**. Ten and a half.

Senator **Weicker**. We would now like to hear from you as to what transpired.

Ms. **Tinsley**. OK. In Joseph's case there have been countless reports of drug abuse, mechanical restraint abuse, physical abuse and sexual abuse. I have seen Joseph restrained, laying in his own vomit and human waste. I have seen him restrained to a chair with a broken arm that they did not even know was broken.

His records show that at times he has been in restraints almost around the clock. He has been given many times the maximum recommended doses of medication such as prolixin. I have seen him outside lying on the ground with his hands tied behind his back, unable to get up.

Appearance-wise he has been disfigured from injuries such as solidified hematomas on both ears, nose dislocations, countless black eyes, numerous lacerations to his head, his teeth have been knocked out, suffered separation of both shoulders, torn cartilage in his knees, hand injuries, and broken ribs.

A review of the record shows the gross violation of his rights as guaranteed by both the United States and the State constitution and laws to his right to education under Public Law 94-142, the right to habilitation and human treatment. Instead Joseph has been dehabilitated. He no longer has the skills that he entered the institution with.

Other advocates and myself have spent many hours in Joseph's behalf. Meeting after meeting and program after program has been written which looks good on paper and serves to satisfy legal requirements, but certainly not Joseph's needs.

We have made complaints from every agency from pest control to the Governor's office, and the complaints were on everything from abuse down to maggots in his carpet. However, we did receive one humorous response, notifying us that our complaint about the roach infestation had been taken care of. They moved his room down the hall.

The atrocities, abuses and stories of human degradation go on, and I have only highlighted a few here.

Parents left with no other alternatives and forced to live with these results are very often destroyed themselves in the process. Joseph's mother today is a bitter, angry, frustrated and sometimes totally irrational person when trying to speak of her son.

Although I speak of only one personal experience here today, getting relief for Joseph is not my only goal. There are hundreds of Joseph's in Georgia and thousands in the United States, and somebody has to speak for them.

Handicapped people do not shed their rights at the institution gate.

It must be realized that persons with autism and other severe disabilities will always depend, to a degree, on support from a service system. Deinstitutionalization translated to mean isolated placement in the community without support or social ties is not the answer. The goal has to be community placements that improve the quality of life not worsen it.

The point has to be made again and again that human beings and handicapped people are suffering outrageous human indignities, even though adequate Federal and State laws exist to assure the rights and protection of the handicapped. They must be enforced. Most families cannot financially afford to pursue the legal rights of their children, while on the other hand, State agencies have unlimited financial resources. They use your tax dollars with which to fight the very people they are being paid to serve.

We cannot remain hypocrites and advocate for the right to life and demand that heroic efforts be made to save the life of every handicapped child that is born without making the same heroic efforts to give them a life worth having.

[The prepared statement of Ms. Tinsley follows:]

STATEMENT OF MARY TINSLEY , VOLUNTEER ADVOCATE FOR THE RIGHTS OF THE HANDICAPPED, GEORGIA

Senator Weicker and members of the subcommittee, it is a great personal pleasure to appear before you today.

I am here to speak on behalf of Joseph Griffith as a concerned citizen and advocate. Although I am before you to talk about my personal experiences with one person, getting relief for Joseph is not my sole purpose, there are hundreds of Josephs' in Georgia and many thousand in the United States.

Joseph Griffith has a diagnosis of Autism and Mild to Moderate Mental Retardation. Autistic people, by their nature and rather bizzare behavior, are probably the least understood of all the institutionalized population and therefore more likely to be abused than others.

The history of services for persons with Autism and others with severe behavior problems parallels that of other disabled persons because there were not many, in most cases not any, appropriate community-based residential programs. Families were left with two alternatives:

1. They could keep their children at home with little or no support, either from the schools (prior to the implementation of P. L. 94-142) or from the medical profession, or
2. They could place their son or daughter in a large state institution.

History also shows us that the success rate for the institutional treatment of mildly and moderately handicapped persons is not high; it has been negligible for person with Autism or behavior problems.

Overcrowded living conditions and the lack of sufficient numbers of competent, trained staff, in addition to the lack of programming, served only to exacerbate a person's behavioral problems. Constant use of chemical and/or mechanical restraints was not uncommon. If a treatment program was available, it was usually ineffective and carried out by people with little or no understanding of its purpose.

While data can be gleaned from studies to support programs which eliminate unacceptable behaviors through the use of punishment, there are almost no studies, especially those involving persons with severe disabilities, which provide any data showing that the special treatment programs provide a real increase in the quality of life for its consumers.

The person about whom I will speak today is a product of these institutions and representative of many, many more persons in institutions everywhere.

Joseph Hill Griffith, now twenty-three years of age, was institutionalized at age twelve and a half years (pictures one and two). Ten years in the State of Georgia's institutional system has taken its toll on this young man and resulted in the systematic destruction of a human being. Joseph was placed in the Georgia Mental Health Institute in 1973 after the death of his father. During the next seven years, there were many reports of drug abuse, mechanical and physical restraint abuse, physical abuse, and sexual abuse - all of which is difficult to prove as you know. Even eyewitnesses and medical examiners do not want to come forward and testify for fear of retaliation which might lead to loss of employment. Some simply do not want to be involved even though they are required by law to report abuse.

I first became involved with Joseph at the request of his mother in 1980. He was nineteen years of age at that time. He had just been transferred from the adolescent ward to the back ward of an adult unit at the Georgia Mental Health Institute without any notice to his family.

When I arrived at that institution for the first time to see Joseph, I found him in a small seclusion room in an abominable condition. He appeared to be heavily medicated and was lying on a bare mattress, spread-eagle in four point restraints. When I inquired as to why he was in restraints, I was told that he was violent and dangerous to himself and others. I was also told that he was kept in restraints a lot of the time. These mechanical restraints were made of a hard plastic mesh (similar to that used to make patio furniture). They were locked with a key around each wrist and ankle and a short tether was attached from each cuff to his bed. They were also illegal.

The violent behaviors which were exhibited by Joseph and said to be the reason for which he was kept in these restraints were described as follows: opening and closing doors; flipping light switches on and off; running; jumping up and down on furniture; threatening to break things; and trying to headbutt staff when they attempted to put him in restraints. I saw no effort made to redirect this behavior. In my opinion, since Joseph was given nothing to do, I think that he was simply bored to death and this was the way in which he amused himself.

During the next five months that Joseph remained at GMHI, I found him in life-threatening situations numerous times. Examples of these include: being restrained on his back behind a locked door while lying in his own vomit, in addition to being soaked with urine. When I protested this treatment because I feared that he might choke to death on vomit, the staff's response was to restrain Joseph in a face-down position. On another occasion, I found Joseph to be shaking all over, barely able to walk, with his tongue hanging out, his lips swollen, and he was begging for water. At this point, I tried to get him to drink from the drinking fountain. Because he had lost some control over his facial and throat muscles, he could not get enough suction to drink and I had to get him a glass. I have also found him with his wrists oozing a bloody substance from the restraints (picture three). He was continually begging for his mother and always promising to be a good boy if they would please let him out of restraints.

A motion for a Protective Order was filed in Probate Court to get some relief for Joseph from this treatment. During the course of preparation for the hearing, I was able to have a brief look at some of his records in which I found various discrepancies and clearcut examples of violations of Joseph's rights, some of which I will attempt to describe.

In terms of education, his records showed that he had only been allowed to attend school for two years and that this had occurred prior to his being institutionalized. By keeping Joseph out of school, his human rights as guaranteed by the U.S. and Georgia constitutions, as well as the laws of the State of Georgia, were being violated. In addition, he was denied his right to a free appropriate public education under Public Law 94-142, despite the fact that an educational due process hearing had been won in his behalf a year earlier. Continuously, chemical and physical restraints were substituted for Joseph's habilitative program.

In 1979, an agreement had been reached to place Joseph in a private school in Connecticut but for some reason that placement never occurred. After negotiation between the school system and the State Department of Human Resources, all parties concurred that Joseph did not belong in a state institution. Consequently, they agreed to place him in a private school for autistic children and adolescents in another state since nothing besides the institution existed for him in Georgia.

As a result, Joseph was placed out-of-state in a private school in September 1980. I felt that his program there was excellent (see picture four). He had his own apartment which he shared with a trained houseparent/teacher. Joseph did his own housekeeping which included vacuuming, dusting, laundry, and shopping. He also attended school every day where he learned academics as well as vocational skills. Unfortunately, this placement only lasted six months. I went out-of-town for a month, during which time a decision was made to terminate Joseph's placement there, and I was never given a satisfactory explanation as to why. When I returned home, I found that Joseph had already been placed back in a state institution in Georgia. To my knowledge, neither the school system nor the Department of Human Resources made any effort to locate another school or program for him.

Upon his release from the private school program, Joseph was placed at the Georgia Regional Hospital at Augusta on April 1, 1981. Six months later after undergoing treatment that I am sure would be illegal if used on animals, a treatment plan was written which included the use of psychotropic medications. Psychotropics tend to make Joseph more hyperactive and tend to induce psychotic behavior. For a short time at Augusta, he was still able to attend school but he had a very difficult time since his placement was on an adolescent ward with other adolescents who were not autistic or mentally retarded. My observation was that he tried very hard at first to have a peer relationship with this group but could not. As a result, he was often the brunt of their jokes, and as they teased and taunted him he became more and more confused and hyperactive. He was given more medication and spent increasingly more time in restraints. His mother pleaded with them not to give him thorazine or haldol. Those were two drugs that she knew had adverse effects on him. His records show that he was given these drugs anyway. The records also show that he was given many, many times the maximum adult dosage of powerful drugs such as prolixin, loxitane, navane, moban, mellaril and others. As a consequence, he had to be given more drugs to control the side effects of the first drugs and because he was sleeping very little by this time, he was also given a wide range of barbiturates such dalmane and chloral hydrate. Sodium ambytal was given seven and a half grains at a time at intervals of thirty minutes, one hour, two hours, four hours, and with permission to be given in between if his behavior warranted it. Joseph's condition continued to worsen as they switched from drug to drug until finally he had a grand mal seizure. Then it was decided that he had to have seizure control medicine and dilantin was added to his drug regimen. There was a constant battle with celulitis in his ankles and wrists from the use of restraints. Therefore, antibiotics were added to control the infections (see pictures five and six).

On one occasion while at Augusta, I found Joseph restrained in a chair, with his wrists and ankles tied to the chair and a bed sheet had been wrapped around his neck which criss-crossed under his arms and was tied to the chair in back. The chair was chained to a ping-pong table and another table was shoved up against him in front. As I entered the room, he looked up at me and said, "My arm broke." When I moved the table from in front of him, I could see the massive swelling of the arm and hand under the restraints. I then asked the staff if it was broken. One staff member said, "Oh, no its not broken, that's just edema." I insisted that they x-ray the arm and the x-ray showed it was not only broken, but it had been broken so long that it had started to heal. Even then, they refused to put a cast on Joseph's arm. On another occasion, I arrived to find him outside in a fenced area, on the ground with his hands tied behind his back, unable to get up because he didn't have enough balance. This was done, I was told, to keep him from taking his clothes off. When Joseph's condition deteriorated, he was moved from the adolescent ward to a large room in a vacant building. There he was allowed to run from wall to wall, bang his head, take off all his clothes and go naked. There was no program and no structure of any kind. The result of this was that he lost all learned skills and reverted back to the early infantile autistic behavior. In addition, his weight dropped significantly from about 160 to 104 pounds. Despite all of this, nothing was done for Joseph. His nightmare continued, until he had to be hospitalized twice. The records made at the time of the first hospitalization showed he was suffering from drug overdose, dehydration, and malnutrition. The second hospitalization resulted in his being transferred to still another state institution - in Milledgeville, Georgia.

His placement at Central State Hospital at Milledgeville was on a combative adult locked ward with mentally ill men who were not mentally retarded. This was a poor place for a non-combative retarded person who does not know how to defend himself. While Joseph has a history of aggressive behavior and will hit others, he is not able to plot and deliberately attack someone with the intent to do harm. His condition and behavior at that time was very seriously weakened. He had two staff people assigned to him at all times. The staff psychologist was well trained in behavioral techniques and after working with him almost constantly for two weeks was able to bring Joseph's behavior under control and also to train the staff. It was almost impossible to maintain his behavior, however, because of the restrictive environment. The staff not only had to keep Joseph calm, but also had to keep the other patients from attacking him. The result was that his program ended up being one in which Joseph was not allowed to say or do much of anything. He was constantly told to "sit down, shut up, don't move, keep your legs crossed, keep your hands in your lap, etc." When he did not comply, he was immediately placed on the floor and bodily restrained. This method was called "Quiet Relaxation Training." (See picture 7)

He received several serious injuries during his stay at Central State, which include the following:

1. very large solidified hematomas on both ears
2. nose dislocation
3. numerous black eyes
4. four broken ribs
5. broken finger
6. head split open

When confronted about the injuries, the staff claimed the patient did all this to himself. It was never explained to me how this could happen when I had been assured that two health service technicians (HSTs) were never more than arms length away.

At this point, we felt it was necessary to request a Due Process Hearing under P.L. 94-142 because his existing Individualized Education Plan (IEP) was not being followed and he was spending most of his time sitting in a chair in a hallway. He was also nearing his twenty-second birthday and was entitled to compensatory education. I also wanted him in a less restrictive environment closer to his home. The hearing turned out to be a charade since the school board attorney informed the hearing officer that he did not think that she had the authority to rule on the issue of compensatory education. The Hearing Officer complied with his suggestion and did not rule on that issue. We did not even get a decision until four months after the hearing. We did not get a copy of the transcript for over a year, which is a violation of federal law. (Hearing Officer training in Georgia is conducted by the school system attorneys.)

In the meantime, Joseph was transferred to the Georgia Retardation Center in Atlanta, Georgia. His program remained almost the same as it was at Central State, except that the staff at GRC has little or no supervision. The staff claim that the only training they had was in self-defense, not behavior management. Some had no training at all. One of them, I was told, was promoted from a trash clean-up crew to work with Joseph. But then it really does not require much training if all you are going to do is tell the patient to sit down, shut up, and wrestle him to the floor if he does not comply; or, carry around a kitchen timer and a sack of cookies and give him one every fifteen minutes if he has been good 'till the bell rings. This same staff is expected to teach him in school and in the vocational workshop while some of them do not even have a high school education.

Joseph has received permanent disfiguring injuries while at GRC, which include:

1. separations of both shoulders (see pictures eight, nine, and ten)
2. torn cartilage in one knee
3. his nose has been injured so many times that he can hardly breathe through it
4. broken fingers
5. many black eyes
6. five teeth knocked out
7. severe burns on his legs

I, along with other advocates, his mother, and staff from the Georgia Advocacy Office, have had meeting after meeting protesting this treatment. We have made complaints to every public agency ranging from pest control to the Governor's Office and have received little or no response. However, we did receive good response from the patient's advocacy office informing us that our complaint about the roach infestation had been resolved. They had moved his room down the hall!

A more typical response to complaints is exemplified by the following situation. Joseph's mother witnessed a staff person jerk Joseph around by the hair which resulted in three large bald areas on his head. His mother even picked the hair up off the floor and threw it away. After I filed an internal complaint, the patient advocate conducted an investigation and found that there was not enough supporting evidence so no further action was taken.

The atrocities, abuses and stories of human degradation go on and on, but I realize that my time is limited.

There is one last characteristic of autistic persons which I have failed to mention. Due to the very nature of their condition, they do not have the capacity to lie or make up stories. They often repeat what others have said or will use the terminology of others to express how they feel. So when Joseph complained of sexual abuse to himself- in his own way- he was telling me what really occurred. The superintendent's response, "that another patient had put him up to making such statements," becomes increasingly ludicrous. It seems almost criminal when one stops to think that people such as the superintendent are supposedly the best trained and - more importantly - the persons responsible for the welfare of so many vulnerable human beings.

When Joseph makes statements like: "I don't want no more whippings; I don't need restraints; I don't want you to hurt me no more; and don't hit me," it becomes clear that abuses are occurring and will continue to occur in institutional settings. Given the economic structures and even the physical layouts of most institutions, abuse cannot be prevented without constant supervision of primary care "hands on" staff. This, we all know, is impossible. We must then look to a different model.

Many persons with autism and other severe disabilities will always depend, to a degree, on support from a service system. Deinstitutionalization translated to mean isolated placement in the community, without supports or social ties, is not the answer. Our goal must be community placements that improve quality of life, NOT worsen it.

Even though adequate Federal and State laws exist to assure the rights and protection of the handicapped, they are not enforced. Most parents cannot financially afford to pursue the legal rights of their children; while on the other hand, State Institutions and school systems have virtually unlimited financial resources, (State and local taxes) with which to fight the very people they are paid to serve.

Senator Weicker. Mary, that is pretty concise and right on target. I find it very difficult to equate all the concerns for life in this Nation with the budget cuts that are approved both by the President and the Congress. There is something quite hypocritical and contradictory about all that.

This is rather precious life. This is what we do with life in the United States of America. This is what we do with life in the United States of America?

Ms. Tinsley. In an institution, that is what happens.

Senator Weicker. I want to repeat Mary's words of her prepared statement:

> We cannot remain hypocrites and advocate for the right to life and demand that heroic efforts be made to save the life of every child born with a handicap without then making the same heroic efforts to provide them with a quality of life worth having.

Now, that is the issue. That is one of the issues before this Congress and before the American people.

Ms. Tinsley. That cannot be done in an institution.

Senator Weicker. Mary, what institution are these things taking place in?

Ms. Tinsley. Joseph has been in four State institutions in the State of Georgia, each time hoping that it would be better and each time it has gotten grossly worse.

Senator Weicker. Is there any therapy taking place?

Ms. Tinsley. Very little. What therapy does take place, programs are written, they are left to staff to implement who have very little knowledge or understanding of what the goal of that program is supposed to be or how important it is to that single individual that the program work for him.

Senator Weicker. Are you a relative of Joseph?

Ms. Tinsley. No; I am not.

Senator Weicker. Are you paid by anybody?

Ms. Tinsley. No; I am not. I am strictly volunteer.

Senator Weicker. So I would say that this is about as impartial an evaluation of the situation as we are going to get. You are not family and you are on nobody's payroll.

Ms. Tinsley. No. I operate out of my own pocket.

Senator Weicker. I think you alluded to this, but I just want to get your own views. Do you see other instances of this type of treatment going on?

Ms. Tinsley. Yes, and worse. People in straight jackets for hours and hours and hours. People knocked out on drugs and restrained to a bed for days.

Senator Weicker. Whom do you complain to?

Ms. Tinsley. All the way up the ladder. It does very little good to complain to anybody because everybody knows that the Office of Civil Rights and the Justice Department is a paper tiger. You can write complaint after complaint and they send somebody out to investigate and very often the investigator does not know what they are looking at, are not trained to know what they are looking at, and they go in with sort of a tongue in cheek attitude like, "Oh, you did not really do that to this boy, did you?" And the complaint drags on and on for months.

The attorneys for the Office of Civil Rights are very ultraconservative, and if they do find fault and decide to take action, then they have to send it to Washington for approval, and then Washington sets on it for months.

In the meantime, you have a human being out there suffering. Advocates cannot sit back and just to visit someone everyday and walk away with tear in their eyes and know that that child is going to be hit, beat, maimed, raped, or something before they can get back out there again.

Monitoring has not helped. We have set up a monitoring system for Joseph, and it did not help that much. Close monitoring does not even help. They cannot survive in these institutions. Being placed in an institution is a punishment in itself that they also have to overcome besides their handicap.

Senator WEICKER. Mary, I think I would like to have you on my side when we fight. Let me move to the next witness.

Bruce Goldstein.

STATEMENT OF BRUCE GOLDSTEIN, ESQ., BOUVIER, O'CONNOR, CEGIELSKI & LEVINE, BUFFALO, NY

Mr. GOLDSTEIN. I am August Bartholomay's former guardian ad litem and attorney. August was locked in a shower room at the Craig Developmental Center for several years and allowed out only at mealtimes and when the other residents showed. The justification offered by staff for this inhuman situation was that August was considered to be the worst case of the developmental center. He was bothersome to other residents, and he wanted to be in the shower. He wanted to be.

Augie was described by all involved as an animal who would never be able to feed himself or toilet himself. Had it not been for the efforts and conscience of Lloyd Simpson, the therapy aide who "blew the whistle", Augie might still be in that shower room. When Lloyd learned there was a protection and advocacy system in existence for the protection of the developmentally disabled persons, he contacted that office and was referred to their local attorney, Mr. Joseph Gerken in Buffalo. Mr. Gerken had communications with the State agency concerned with developmental centers. That is the Office of Mental Retardation and Developmental Disabilities in New York State. But after 9 months no resolution was yet in sight. It was at that point Mr. Gerken sought my assistance in instituting litigation on Augie's behalf. A lawsuit was instituted in the western district of New York under the title of Goldstein versus Coughlin.

Although I would have preferred to have made this case a class action lawsuit to better the conditions of mentally disabled and retarded persons in institutions, it was clear to me that my ethical responsibilities were first owed to Augie. Accordingly, a broad-based lawsuit was not possible since this would have resulted in Augie being sacrificed. Thus, the tenor of the lawsuit became one of arranging for proper services to comprise a meaningful habilitation program. The goal from the outset was to get Augie out of the institution and into a community living situation. On April 20, 1984, Augie moved into a community residence where he still remains.

Augie now is an affectionate person who we first saw smile within the last 2 years. He is substantially capable of feeding himself as well as toileting himself. The animal the professionals said would never be capable of self-care is now a human being. We can only guess what Augie would have been able to do had he received proper programming and care at an early age rather than the abuse and neglect that I have indicated in the attached listing.

Just to quickly cite to it, the types of drugs that he received in high doses such as thorzaine, hyoscine, prolisin, trilafon, haldol, ritalin, stelazine, dexadrine, mellaril. It goes on. Dalmane.

He had 10 reported instances of parasites, broken ribs, 30 reported incidents of lacerations, 61 reported instances of infections, abrasions, sores and lesions, 10 reported instances of assaults by other residents, amputation of an infected ear. At one point he had 18 teeth extracted because they were infected.

My recommendation to this committee involves several things, but I am trying to pick some priorities. That is consider reenacting a bill of rights for developmentally disabled persons with a clear congressional intent that this be a bill of rights. The Supreme Court case of Pennhurst State School versus Haldeman struck an almost mortal blow to our efforts in this lawsuit when Justice Rhenquist stated that the rights in the Developmental Disabilities Act constituted guidelines, not rights. In the case of Youngberg versus Romeo, another Supreme Court case, this does provide some assistance, but the language of that case as quoted by the Supreme Court requires considerable deference to professionals, and that leaves much to be desired.

Allow the saga of August Bartholomay to instruct how deference to professionals can work to the detriment of mentally retarded and developmentally disabled persons.

I have a videotape that I brought. It has a short portion at the beginning which was broadcast on a local Buffalo television station, WIVB TV channel 4. After that new report, the tape has selected statements from a videotaped deposition of Lloyd Simpson, the therapy aide, and that deposition, of course, is under oath. The entire videotape deposition is in the possession of your subcommittee staff and available for review.

Mr. Simpson's descriptions of what occur speak for themselves.

[The prepared statement of Mr. Goldstein and taped material referred to follow:]

TESTIMONY OF BRUCE A. GOLDSTEIN

ATTORNEY

BUFFALO, NEW YORK

PRESENTED APRIL 2, 1985
Subcommittee on the Handicapped

I am August Bartholomay's former Guardian ad Litem and attorney. August was locked in a shower room at the Craig Developmental Center for several years and allowed out only at mealtimes and when the other residents showered. The justification offered by staff for this inhuman situation was that August was considered to be the "worst case" at the developmental center, he was bothersome to other residents, and he "wanted" to be in the shower room.

Augie was described by all involved as an "animal" who would never be able to feed himself or toilet himself. Had it not been for the efforts and conscience of Lloyd Simpson (the therapy aide who "blew the whistle"), Augie might still be in the shower room. When Lloyd learned there was a Protection and Advocacy system in existence for the protection of developmentally disabled persons, he contacted that office and was referred to their local attorney, Mr. Joseph Gerken, Esq. Mr. Gerken had communications with the State agency concerned with developmental centers (Office of Mental Retardation and Developmental Disabilities - OMRDD), but after nine months, no resolution was yet in sight. It was at that point Mr. Gerken sought my assistance in instituting litigation on Augie's behalf. A lawsuit was instituted in the Western District of New York under the title of Goldstein v. Coughlin, Civ. No. 79-256.

Although I would have preferred to have made this case a class-action lawsuit to better the conditions of mentally retarded persons in institutions, it was clear to me my ethical responsibilities were first owed to Augie. Accordingly, a broad-based lawsuit was not possible, since this would have resulted in Augie being sacrificed. Thus, the tenor of the lawsuit became one of arranging for proper services to comprise a meaningful habilitation program. The goal from the outset was to get Augie out of the institution and into a community living situation. On April 20, 1984, Augie moved into a community residence where he still remains.

Augie now is an affectionate person who we first saw smile within the last two years. He is substantially capable of feeding himself, as well as toileting himself. The "animal" the professionals said would never be capable of self-care is now a human being. We can only guess what Augie would have been able to do had he received proper programming and care at an early age rather than the abuse and neglect indicated by the attached listing of medications and afflictions he incurred.

My recommendation to this committee is that it consider re-enacting a Bill of Rights for developmentally disabled persons with a clear congressional intent that this be a *Bill of Rights*. The case of *Pennhurst State School v. Haldeman*, 101 S. Ct. 1531 (1981), struck an almost mortal blow to our efforts in this lawsuit when Justice Rhenquist stated that the Rights in the Developmental Disabilities Act (42 U.S.C. 6010) only constituted guidelines. The case of *Youngberg v. Romeo*, 101 S. Ct. 2452 (1982), does provide some assistance, but the language of the Supreme Court requiring considerable deference to professionals leaves much to be desired. Allow the saga of August Bartholomay to instruct how deference to professionals can work to the detriment of mentally retarded and developmentally disabled persons.

The videotape you will see has a short portion which was broadcast on a local Buffalo television station (WIVB-TV, Channel 4). After that news report, the tape has selected statements from a videotaped deposition of Lloyd Simpson, in which Mr. Simpson testified under oath. The entire videotaped deposition is in the possession of your subcommittee's staff and available for review. Mr. Simpson's descriptions of what occurred speak for themselves.

Respectfully submitted,

Bruce A. Goldstein

BAG/lmh

CHRONOLOGICAL OUTLINE - BARTHOLOMAY

1. 1937-August (Augie) Bartholomay born
2. 1941-Entered institution
3. 1941 through March 1979:
    - a. virtually no programming, treatment, education or training
    - b. frequently placed in physical restraints (camisoles or restraining sheets); orders often issued for days or weeks at a time
    - c. over-medicated (see attached listing)
    - d. numerous diseases and infections (see attached listing)
4. April 2, 1979, lawsuit commenced [*Goldstein v. Coughlin*, Civ. 79-256 C, U.S. District Court, Western District of New York]
5. May 9, 1979, Bruce Goldstein appointed guardian ad litem.
6. 1979-October 1982 the following services were provided:

    Speech, Physical Therapy, Occupational Therapy, Recreation Therapy, "Education," and instruction in activities of daily living
7. October 1982-Augie entered Doty Day Treatment Program
8. March 1983-Augie entered Van Rensselaer residence (environment was somewhere between an institution and a community residence)
9. November 9, 1983, deposition of Lloyd Simpson (see videotapes)
10. April 6, 1984, conditional Stipulation of Dismissal filed with District Court
11. April 20, 1984, Augie entered Heath Building (self-preserving community-based ICF - a community residence)
12. October 20, 1984, case dismissed

Listing of Drugs Received While in Institution
With Typical Dosages

Thorazine (PRN 100 mg IM; 150 mg IM; 200 mg QID; 300 mg QID; 400 mg QID)

Hyoscine (plexonol) (hypo gr. 1/100)

Trilafon

Prolisin

Sodium Luminol

Haldol (5 mg BID)

Quide (40 mg TID; 30 mg QID; 165 mg/day)

Ritalin (10 mg QID)

Stelazine

Serentil (25 mg IM; 50 mg TID)

Dexadrine (5 mg TID)

Mellaril (200 mg QID; 100 mg QID; 150 mg QID)

Sparine (100 mg IM, PRN)

Benadryl

Valium (10 mg IM)

Chloryl Hydrate (500 mg Syrup)

Dalmane

Diseases, Infections, and Similar Afflictions

Up to July 1979

Parasites (e.g., pinworms): 10 reported instances

Boils: 6 reported instances

Tumors and Cysts: 2 reported instances

Broken Ribs: 1 reported instance

Lacerations: 30 reported instances

Infections, Abrasions, Sores, and Lesions: 61 reported instances

Assaults by Other Residents: 10 reported instances

Amputation of Infected Ear

Teeth Lost or Extracted: 2/28/64, 12/28/64, 3/17/73 (lost teeth when kicked by another resident), 5/21/73, and 8/8/73 (18 infected teeth extracted)

VIDEOTAPE VOICE. August Bartholomay seems to thrive on affection these days. Amazing say those who know about his past. Augie, as he is known to his friends, has spent 42 of his 47 years at the Craig Developmental Center for the Retarded where, according to sworn testimony by a former aide, he was locked away in a shower room for at least 3 years because of antisocial behavior.

Mr. **SIMPSON** on videotape. He was locked in the shower room 24 hours a day, 7 days a week with the exception he was left out at mealtime.

VIDEOTAPE VOICE. These pictures of Augie begin at age 5 when he was committed to Craig show his change of appearance. An ear was amputated. Parasites invaded his body, and he suffered lascerations and a broken rib while in the institution.

Today, thanks to his guardian and attorney, Bruce Goldstein of Buffalo, who sued the State, Augie has been placed in a home-like setting with a special program designed to meet his needs.

Mr. **GOLDSTEIN** on videotape. He has an overwhelming ability. From the time that I first met Augie he was like an animal, a wild man, and today he is a human being.

VIDEOTAPE VOICE. Some of the brightest moments of Augie's life these days are shared with his sister Elena who had grown up not even knowing her brother existed. Now there is a special closeness between them.

Ms. **ROSE** on videotape. He is smiling. I think it was in 1980, I think, it was the first time he had smiled for the first time.

VIDEOTAPE VOICE. Nobody knows how many more Augies there may be in other institutions, but for Augie Bartholomay life is beginning again at the age of 47. Rich Newberg, News 4, Saranac, NY.

Mr. **GOLDSTEIN** on videotape. When Augie was in the shower room, would you describe what his activities where in the shower room?

Mr. **SIMPSON** on videotape. From observing him, he was constantly taking his pants off, putting them back on again or from time to time, getting to his feet and then throwing himself down on his mattress, sort of bending over towards the mattress. In the last couple of feet he would throw himself on it.

The shower room was like almost a ceramic tile floor, and it had three bays for showering, and one area, as you walk into the shower room on your left it has approximately I would say about a 4-by-4 area with a sill that was raised up 5 inches if a resident became incontinent, you used to place them in that area, and you had to sort of a forceful shower that you could wash them down and rinse and clean them off.

He is not social. He goes and if you let him mingle in ward, he takes the clothes off the other residents and pulls the clothes off the bed and generally raises havoc so that that is why they keep him locked up in the shower room.

I spoke to some of the people that work there that were in charge, a Mrs. Gilson who is an RN, Mr. Migliari also an RN, and Mrs. Teresa Frazier who was nurse administrator who is also an RN, and I said, "Why is this this way? Why is he kept like this?" "Well, we do not have anyplace to keep him." I said, "If I owned a dog and I could not keep him in better conditions than this," I said, "I would shoot the dog."

I said, "Where in the hell is his mattress?" They said, "Well, he has a bed in the ward now so we are not allowed to let him have a mattress in the shower room." So there was a bed in the center ward, and it had his name either in tape or something with his name August Bartholomay on the bottom of this, but I never observed him in that bed sleeping, sitting or anything. He was in the shower room with one thin cotton sheet.

Mr. **GOLDSTEIN** on videotape. What was underneath him?

Mr. **SIMPSON** on videotape. A hard ceramic-type floor.

At one time, I do not know, maybe more than once, he developed pinworms off and on because he was on the floor laying around on the floor and he would have his fingers in his mouth, touching his anus or whatever, rectum, whatever you want to call it, and he just did not know any better and he developed pinworms.

I had an interest in him and I enjoyed working with him. Sometimes a hell of a lot more than I do what I am doing now, and I enjoyed seeing him be there. He is more brighter than I am and maybe Mr. Hunt over there, but his hair now is growing out nice. He wears clothes, something they said he could never do.

In fact, we went over to the Dowdy the other day. It is a building that they go for programming. He held up his hand. He shook hands with me. A pretty nice feeling to see somebody do this that people said this is impossible. He is an animal.

[Videotape concluded.]

Senator **Weicker**. Mr. Goldstein, would you like to continue or shall we now hear from Elena Rose?

Mr. **Goldstein**. I would hear from Elena.

Senator **Weicker**. Elena, nice to have you with us.

STATEMENT OF ELENA ROSE, BUFFALO, NY

Ms. **Rose**. Thank you.

I first found out about Augie in 1976 through a friend of the family. I had confronted my mother and said it was true. I wanted to know why it was kept a secret for so long. She had told me that my father had been married before. His wife had been killed and he had his son put away because of seizures. I had questioned her as to what kind of seizures. This being important to me because I have three children of my own, and were these seizures hereditary. She had no answers for me so I decided I would find out for myself.

It was in August 1978 that my friend Genny and I had gone to the Craig Developmental Center. When I first encountered Augie, he was being led to me by someone holding a cookie in front of him. He was hunched over, shuffling his feet. He looked deformed. He had no teeth. He had one ear missing, and he was making these horrible sounds.

I was then told that he had his own room because of his antisocial and violent behavior. I was told that he was considered lower than an animal in the gutter because most animals would not eat their own feces as he has. I was also told that he was profoundly retarded and to never ever expect him to be any better than I had seen him then. I actually believed all this. I believe it until I spoke to the Protection and Advocacy and Bruce Goldstein. When the lawsuit was started, Augie made a complete turnaround.

Today Augie is living in a home-like setting, attending day programs. He is very social, lovable, puts out his hand to greet you, bends his head over for you to give him a kiss on the cheek, smiles most of the time and is really in a happy state of mind. In October 1974, I became Augie's legal guardian.

Now, after 44 years in the institution, my brother is starting to speak. Two months ago I heard him say "Mom" and the staff has told me he has said four other words.

Senator **Weicker**. I do not really think there is much to add in the way of questions. I think maybe what we will do is have Bonnie testify, and then if there are questions for the whole panel, we will ask those at that time.

Bonnie.

STATEMENT OF YVONNE OLENICK, MIDDLETOWN, CT

Ms. **Olenick**. My name is Yvonne Olenick, Bonnie. I live in Middletown, CT. I am the mother of two daughters with mental retardation, secondary to PKU. One daughter, Ann Marie, is institutionalized. The other daughter, Patricia, lives at home and has attended public schools and works in an outlet store sponsored by our local ARC. I also have three other living children.

My daughter, Ann Marie Olenick, was admitted to Mansfield State Training School on February 10, 1961. She was 5 years and 9 months old. This would have been kindergarten age for a normal child. Ann Marie has never attended school, although there was one on campus, nor did she attend special education classes in the local public schools. She received no programming, self-help skills training nor vocational training. Her teeth were brushed for her. She was bathed, fed, and diapered. Her day consisted of sitting on the day room floor between meals and diaper changes. Over time her leg muscles atrophied.

When she was 18, a well meaning aide taught her to feed herself. Since this was not a properly designed program, she must now be retrained because she finishes her meals in less than 2 minutes with no chewing and virtually no swallowing.

Whenever we would visit Ann Marie, there the residents would be, some sitting on the day room floor, some were tied to toilets in the doorless units and others were having their diapers changed in full view of other residents and visiting, and lest you think this came from yesteryear, the last time this happened was November 17, 1984, causing my husband, our daugther Patricia and me modifying embarrassment. These are adult men and women.

After several years of this environment and lack of stimulation, Ann Marie started banging her head on the floor or on the tray of her geriatric chair. She also began slapping her head and ear. These behaviors have resulted in a large mass on her forehead and a swollen cauliflower type ear.

She was given psychotropic drugs, Mellaril and Thorazine, for over 20 years with no improvement in behavior. She was also given Dilantin for epilepsy which she does not have. She had never had a seizure of any kind at Mansfield. The last 5 years have been a nightmare struggle for medication reduction. She is currently on a drug-free regimen. Maladaptive behaviors have increased somewhat, but the continuing lack of day programming contributes greatly to this.

Due to the intervention of the panel of monitors of the consent decree, CARC, et al., versus Gareth Thorne, et al., Civil Action No. H-78-653, Ann Marie is eligible for functional education off the residential unit, and has a one-on-one aid on the unit. Eligible does not mean much. The program is of short duration and frequently cancelled. Our current goal is to upgrade the program and add continuing functional education on the unit.

In addition to psychotropic drugs, restraint is another method used to deter head banging and self-abuse. Procedures used have included helmeting, safety cuffs, four-point restraint, arm splints, and mitts. In 1981, she was restrained by these methods 786 times. Only the helmet is currently in use.

A program has been designed by a private consultant to eliminate negative behaviors without the use of any type of restraint, helmet or drugs. Implementation of this program will take time, that is, staffing, funds, and team meetings.

Having a one-on-one aide should reduce the occurrence of injuries. I am including a list of casaulties appearing in her records. I would like to mention here that the diagnosis for traumatic bursitis was made in 1971 and not treated until 1981; 10 years of pain says neglect to me.

The casualties appearing in her records, and these are taken right from her Mansfield records. It is a summary of 1963 to 1982. 1982 to 1984 are not available.

Fifty-five injuries to forehead and chin; 34 trauma to knees; 20 injuries to wrists; 12 injuries to eyes; 16 injuries to mouth, including two fractured teeth; six incidents of respiratory infections and pneumonia; 19 occurrences of rashes; two pharyngitis and also gingivitis, ring worm, Vencent's infection, and boils.

The hope for Ann Marie lies in her post institutional plan, a small, highly structured group home in the community, handicapped accessible, housing four or fewer clients, with consultants in occupational and physical therapy, psychiatry, psychology, social work, and nursing skills.

Being a named plaintiff in the previously named lawsuit mandates his plan, and although roadblocks seem to keep popping up—suddenly it has to be an ICF/MR unit—I can return to court to secure its implementation.

I have, of course, focused on my daughter. I do not, from my observations, think her case atypical.

How many more institutionalized people are receiving no programming, too much medication, too many hours of restraint, injuries self-inflicted and otherwise, no privacy, no respect?

Too many, far too many.

Senator WEICKER. I think the stories of Joseph and Augie and Ann Marie certainly make difficult listening. I am glad the lights were out, for example, when I saw the video. I am sure a lot of us in this room were glad the lights were out.

But the stories we hear are not worth a damn unless they make a point, and that is what brings us all together.

Mr. Goldstein, you state that you became involved with Augie after an unsuccessful 9 month attempt by the Protection and Advocacy Program to end the abusive conditions in which he was living. Do I understand you correctly that, even after these conditions were brought to the attention of State officials, nothing was done?

Mr. GOLDSTEIN. That is correct. It is the old self-fulling prophecy. They said he was an animal. They said he was the worse case at the institution. Nothing could be done. This was the only way to deal with the situation.

In fact, that institutional mentality, that bureaucratic and institutional mentality is a problem that is experienced by all retarded people. If I may, Senator, one of the things I heard that we should be aware of and we are not is that there is a distinction between mentally ill persons and mentally retarded persons.

Some of the conditions that we have heard do apply across the board, but how we deal with that and how we meet the needs of those handicapped persons are quite dissimilar between those who are mentally ill and those who are mentally retarded.

In the area of the mentally retarded, we are talking about the lowest substrata of society. These are people who cannot even advocate on their own behalf, and as a result, the self-fulfilling prophecy that is created by the people who are supposed to be taking care of them—these people who are being victimized cannot even speak for themselves.

Here we had a case with Augie of 9 months that the State structure and hierarchy knew of the situation and they were looking into the situation to see what might or might not be done.

Senator **Weicker**. Yesterday we heard from a parent whose case involving abuse against his handicapped child was rejected by nine attorneys. Evidently attorneys are hesitant to take cases involving the rights of the handicapped people in institutions.

I might add this is not a criticism of attorneys. I am one myself, but I must confess I had no feeling of pride when I heard that little statement made.

Could you explain to me why this possibly might be the case?

Mr. **Goldstein**. Surely; attorneys are no better nor no worse than the rest of society, and we do not provide adequate compensation for attorneys. I happen to have an interest in the area of the handicapped and have tried to get as involved as I can, but there is a limit even to what I can do.

There is a question, in many instances, of entitlement to attorneys' fees in the first instance. In fact, you, in another area, are the sponsor of a bill in the read of education of the handicapped, an area in which I like to practice, but I have to stop practice until there is some clarity whether there would be entitlement to fees. You cannot feed your family and make a living, and I am not talking about any rich living, if you cannot get paid for the time you put in. There is a limit to how much you can put in free.

Beyond that, when you are assured that you would be eligible for fees, then you must have a law that will provide when you win you will get paid. Then you got to roll the dice. Some of us are willing to do that. Many are not.

Then if you win, after you have had a particular law that permits you to get fees from the other side, then the amount of compensation is sorely inadequate. It is an hourly rate that is nothing comparable to what is available in the remainder of the practice, and it is something that you get down the road after many years in litigation. You get no recognition of the fact that you have gone all those years without getting paid.

So, for the typical practitioner, you are looking at an esoteric area of law where the rights are difficult, where the proof is very difficult because you are talking about an institutional situation where you cannot get to the information. The wagons become circled, and you cannot prove your case, and the likelihood of winning is very slim.

When you couple that with the fact that you are never going to get paid or very inadequately paid, that is why attorneys do not even want to look at it.

Senator **Weicker**. Elena, your brother endured the most inhumane conditions for 44 years and it took a lawsuit to get him out. Yet after a small time in the community residence, he is speaking. He is dressing himself. Forty-four years, and yet after a short time these things which you have talked about are happening.

I would like to know just what it is that can accomplish this, in the sense that our greatest professionals and our greatest system in the world seems to fall flat on its face. And I would like to hear from you as to what you think, what you attribute to Augie being what he is, what he always was, a first class citizen, but having that taken away from him, and now a first class citizen again. How did you do it?

Ms. **Rose**. Care; a lot of care. That is all I can say, the people that are concerned up there. Augie had been on a one-on-one when the lawsuit was started, when he was removed from the Caighouga Building to the Wilkinson Building, and he was getting special attention.

Personally I did not think it was fair on the others neither. But there were so many people up there that cared for him. That is all I can say. It can be very simple care.

Senator **Weicker**. Tell me something. In this particular case, you had an attendant at the hospital that was willing to stand out and speak up for Augie. What if he had not come along?

Mr. **Goldstein**. If I may, that is the key in that case, and it is the key, unfortunately, for all retarded persons. On the one hand, having an institution is an abuse in and of itself. Unless there is a specific medical need, no retarded person should live in any institution. There is no justification for it. It in itself is a dehumanizing situation. We should tear down the institutions.

If someone has a medical need, put them in a hospital or in a nursing home. If they do not have a medical need, put them in a community residence where they have a home like setting that is caring and as normal like as possible.

Then on top of that, if we would have advocates who are required third party independent advocates. Your suggestion earlier, I think, was a very good one in terms of having some kind of an inspector general or the like.

However, that is only going to be able to deal with the abusive or the egregious situations that we see here. What gets slipped by the wayside and which is not going to be attended to is the day-to-day neglect that occurs on behalf of retarded people, the languishing around, the lack of programming, the lack of interest, and the only way that that can be dealt with, I think, is to have in those instances where there is not a family member or someone who is going to advocate on behalf of the retarded person, because the retarded person cannot speak up for themselves—we are talking about severely, profoundly retarded people, then I think there has to be a third party advocate assigned who will be there on a regular basis to make sure that what is necessary is being done.

Senator **Weicker**. Bonnie, the situation at Mansfield, you have lived with this for how many years?

Ms. **Olenick**. Twenty-four.

Senator **Weicker**. How much, if any, improvement have you seen over that 24-year period? Is it pretty much the same today as it was 24 years ago?

Ms. **Olenick**. Pretty much the same. As I said, last November when we visited, after the Justice Department had walked through at the early stages of the lawsuit, testifiers from our State and other States had walked through, legislators, attorneys, and everyone and had just decried the conditions of the flies and the feces and the smell and the people laying in their own excrement and vomit, and you walk in and it is still the same.

They have moved Ann Marie out of the hospital wing into a group home, what they call a group home, and it is still the same.

The institutional mentality follows the employees around the building, and I am sure will follow them around the State, unless you have them retrained, if possible.

Always value the human being first. Once you value the human being, the other things tend to fall in place. You would not treat that person that way if you valued him. I think training is the key.

Senator **Weicker**. Bruce, did all this matter occur while Clarence Sundram's commission was in being or did this occur before that? In other words, this is a New York State condition we are talking about. I was impressed with Sundram's operation.

Now, did this happen prior to that being set up?

Mr. **Goldstein**. It did happen prior to that being set up. I like Clarence Sundram's operation also, but you have to recognize there is a limit. They are akin to, say, the inspector general. It is only when they find out about something that they come in. It is what we do not know that scars me, and unless there is somebody assigned to each retarded person, you only find out about selected instances, and you do not find out about all the other ones, and Clarence can only operate on what he knows, and he is not in a position to be there checking on each resident.

Senator **Weicker**. Are there any further statements that anyone might have at this time that they would like to present to the committee?

Ms. **Tinsley**. I would like to emphasize again that when you spoke of the Bill of Rights and changes in the certification process, more training and personnel, those are only partial solutions.

Community programs and the redesignation of medicare funds to the community placement that have a home-like setting and as Mr. Goldstein just said, these people need to be in family-like community settings unless they are physically ill and cannot be taken care of at home. We did much better.

Senator **Weicker**. I have heard your opinions relative to the Justice Department as being of assistance, which I gather is about zero in your book. Has anyone else had any contact with the Justice Department in any of their situations here?

Mr. **Goldstein**. It is the lack of contact as far as I can see it, Senator. I never had any contact with anyone from the Federal Government, never seen them ever involved in the development center. I am sure they come by and check the paperwork occasionally.

But I just never see them getting involved in any of these situations.

Ms. **Olenick**. The Justice Department was very active in our lawsuit in the early stages.

Senator **Weicker**. This was when?

Ms. **Olenick**. Over the past 6 years. I cannot give you the exact dates.

Senator **Weicker**. The 1970's?

Ms. **Olenick**. Yes, and up until the election of President Reagan, and soon after that, they were pulled out of the case. [Laughter.] I cannot give you that exact date either, but his first election, and then they were pulled out after that.

The only way we could pursue this was through the Legal Aid Society which is no longer handling our case, but he is doing it on a pro bono basis for us.

Senator WEICKER. Counsel indicates to me that the Justice Department was active in the case until Mr. Reynolds came in, at which point they take of role of the State of Connecticut in this matter, is that correct?

Ms. OLENICK. Yes.

Senator WEICKER. Backing off from the advocacy.

Ms. OLENICK. We lost a good ally.

Senator WEICKER. Also while we are here, and this is not to the point of this panel, but statements were made last night owing to my good friends in the neighboring State of Maryland, and this matter is covered in my report, that, the Justice Department has been very prompt and accommodating insofor as investigating matters in Maryland.

I saw that on the television last night. And the reason I was surprised is that at the hearings we held in November 1983, that was not the story that came through. So I had staff go back. And I think that I would like to give you all the chronology of the promptness of the Justice Department as it related to the Rosewood Center in Owings Mills, Maryland, which was the subject of my earlier hearings.

Their intent to investigate letter was published in, November 1980. In February 1982, there was a letter of findings, and in January 1985, there was a consent decree. So we are talking about 4 years and 2 months.

Now, I think we have all seen throughout the course of these hearings, that State by State, either State action or Federal action has invariably taken more than 2 years.

But if anybody in this room considers 4 years and 2 months a good show for coming to the assistance of those in special need, God help us all when our time comes.

I was joking with a reporter out here at the end of the hearings yesterday on this subject matter.

He said, "Well, really, are not the present laws on the books, are they not somewhat adequate?" And I said, "They certainly were." There are good laws on the books. I am not saying they should not be fine tuned as I have described, but much depends on the people that are supposed to be in charge of enforcing them.

I will be honest with you. I then turned to the reporter in a joking way and I said, "God forbid, and it would make a lot of Republicans ill but if I were President of the United States, I think I would have my Attorney General, on the basis of the law as it is today, move on these matters."

So it is not that we are devoid of authority. We are not. Let us not kid ourselves on this point. The Nation as a whole, not just the Attorney General, is just setting aside these laws and figuring we will just go slow on them.

Do you know what the real shame is here? Do you know why we are going slow in large measure? We have got a budget problem. How are we going to solve our budget problem? We are going to solve our budget problem with Joseph and with Augie and with Ann Marie and with Chris and with Jonathan. That is how we are going to solve our budget problem here in the United States.

I do not think I would particularly care to go to bed living with that. I should hope the country would not either. If we are going to take it out of somebody, let us take it out of ourselves.

In any event, I thank you very much for your testimony. Again, I hope this inspires others to take on the role of advocate.

I might add, Bruce, that I have already made up my mind. I am speaking before the Hartford County Bar Association on Thursday evening, and I think I already know what I am going to talk about. It has something to do with lawyers getting involved a little more than they are right now.

The following statement of Barbara A. Thompson, parent, and the JCAH report will be received for the record without objection.

[The prepared statement of Ms. Thompson and the JCAH report and additional information supplied follows:]

TESTIMONY BEFORE THE SUBCOMMITTEE ON THE HANDICAPPED REGARDING CARE AND ADVOCACY FOR MENTALLY DISABLED PERSONS IN INSTITUTIONS.

Barbara A. Thompson, Parent

My daughter, Susan Marie, age 17, is a resident at Hissom Memorial Center in Sand Springs, Oklahoma. Susan is a non-verbal, multi-handicapped child, a victim of neurologic damage and a chromosome disorder who uses a wheelchair. She was admitted to Hissom on February 28, 1984. She was placed there because I was unable to continue to care for her personal needs. I am a single parent and must work to support a family of three. My other daughter is normal in every respect. Because of a lack of community services, placement in an institution became necessary. I am very concerned with Susan's welfare and training.

Cottage 17 West, in which Susan resides, has a total of 24 girls. Three aides, or cottage personnel, staff this cottage each shift. Of the 24 girls, 8 girls of normal adult size use wheelchairs. 16 girls are ambulatory. On the 11 PM to 7 AM shift, there is one attendant. In the event of fire or a natural disaster, there is no way one attendant could care for 24 girls. Hissom is in violation of fire codes and severely understaffed. Privacy is non-existant in cottage #17. 24 girls sleep in a dormitory. There is one bathtub with no privacy curtain, nor is there a privacy curtain around the toilet. My daughter is tied to the toilet chair to prevent falling (she has fallen off the toilet on three occasions, hurting her face and breaking her glasses. She has no protective reflexes). The toilet chair has arms. The toilets do not have safety rails. Susan's clothing is placed in cardboard boxes on shelves with her name on them. The clothing is kept in four different locations. One closet area in the dayroom is locked. There is no way that Susan can reach her clothing from her wheelchair .

When Susan was admitted to Hissom, she had a testable vocabulary of 87 manual signs, plus the use of a Blissymbol language board. She was able to choose her own clothing and communicate her needs through these two methods. She no longer chooses her own clothing, and uses at most 10 signs. Staff in the cottage are not trained in the use of sign language. Susan resorts to grunting now to get attention.

In November of 1984, the "Unit System" was put into effect. This system made administrative personnel easier for a parent to contact, and supposedly made more and better training available to residents in self-help skills. Attached is my daughter's "before and after" schedule. The self-help skills are taught by non-professional people in the cottage from 5:30 to 6:00 PM. With each attendant responsible for 8 girls, little is taught to anyone.

Toys are few. Supervisory attendants on the day shift believe toys should be hidden away during the daytime so that residents will not refuse to go to the few activities

Barbara A. Thompson

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TESTIMONY BEFORE THE SUBCOMMITTEE ON THE HANDICAPPED REGARDING CARE AND ADVOCACY FOR MENTALLY DISABLED PERSONS IN INSTITUTIONS.

Barbara A. Thompson, Parent   Page Two

they have scheduled. TV is mounted on the wall, with residents craning necks to look up at it. My daughter does not watch TV, and many others do not as well. Coloring books, catalogs, magazines, are not easily available to them. This results in boredom and injury to self and to others.

Medical staff is inadequate. One physician who had been on staff for 7 years is now in court because it was discovered he was never licensed nor did he attend medical school. The administration of Hissom was aware of this fact several months before action was taken. Other physicians on staff are limited licensed, able to practice in institutions in the state of Oklahoma only. A recently hired physician from India is not listed in the 1984-1985 AMA guide.

Ancillary services can and are cancelled at a moment's notice. On March 29th, activities were cancelled for the residents while teachers attended a "Dance Therapy" day. Residents were left with no activities. School consists of one hour or less per day for some children. The Sand Springs School System is contracted by Hissom Memorial Center to provide education for the residents.

Because of the severe shortage of staff, "floats" are used in the cottages. It is rare to see the same face more than once a week. These people cannot know the resident they are supposed to train in self-help skills when teaching these skills depends on repetition. Caseloads for professionals at Hissom are so large that proper attention cannot be given to residents. Direct care workers are inundated with large amounts of paper work. Veiled threats of dismissal are given direct care workers should they use common sense approaches to cleanliness and personal hygiene for residents. For example, Vaseline cannot be applied to the chin of my constantly drooling daughter without a doctor's order. When an acne preparation causes Susan's skin to be dry and cracked, the medicine cannot be stopped without a doctor's order.

The current administrator of Hissom has agreed to re-assignment. He leaves behind a gentleman in charge of the Cottage Life programs who is resistant to any and all changes. He has no training or experience in the field of mental retardation, and definitely is not commited to change of any kind. At this moment, there is no one in direct charge who could implement the broad and necessary changes with a true commitment to their necessity.

Few group homes are available in the State of Oklahoma. Little effort is put forth to establish community programs of any kind. Many residents remain at Hissom when they are able to be working, productive members of society because of this. There simply is no place for them to go. Current plans will provide a maximum of 60 beds in the entire state during 1985. There are 1600 residents in institutions in Oklahoma.

Barbara A. Thompson

TESTIMONY BEFORE THE SUBCOMMITTEE ON THE HANDICAPPED REGARDING CARE AND ADVOCACY FOR MENTALLY DISABLED PERSONS IN INSTITUTIONS.

Barbara A. Thompson, Parent Page Three

I have communicated these concerns of mine to the Governor, his Task Force, the Administration of Hissom, and to the Director of the Department of Human Services as well as the Assistant Directer For Developmental Disability Services. They no longer answer my letters, or respond in any way. I don't know where to turn for help in this matter any longer, unless you can intervene on behalf of the children in all three State Schools in the State of Oklahoma. There seems to be no way to enforce Federal Regulations in this State. Mandates are ignored, and PL 94-142 is ignored as well. The residents of these institutions are human beings, even though mentally retarded. They experience joy, sorrow, fear, humiliation, pain; just as you do. Please help them to enjoy a better quality of life.

Barbara A. Thompson

Barbara A. Thompson
10303 East 12th Street
Tulsa, Oklahoma 74128
(918) 835-2923 - Home
(918) 455-4451 - Work

FALL '84 - SUMMER 85 [illegible]

[illegible] -2213

Client: [illegible]

[illegible] #1

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
5:30	Get Out of Bed						
6:00	Dressing						
6:30	Combing Hair						
7:00	Breakfast						
7:30	Toothbrushing						
8:00	Prepare for Daily Activities						
8:30						Cottage Chores	Prepare for Church
9:00	[illegible] Therapy →		[illegible] Therapy		OT		
9:30			[illegible] Therapy		[illegible] Therapy	Cartoons	Church
10:00	Physical Therapy....						
10:30	School Class #25 10:30 - 11:30 Mon - Fri						
11:00							
11:30	Lunch						
12:00	Oral Hygiene Skills						
12:30							
1:00	ART				Music Therapy	Music	
1:30		[illegible] 1:30 - 2:30		[illegible] 1:30 - 2:30			
2:00							
2:30	School Activities 2:30 - 3:30 Mon - Fri.						
3:00							
3:30		[illegible] Therapy		[illegible] Therapy	Swim		
4:00							
4:30	Personal Hygiene - Prepare for Supper						
5:00	Supper						
5:30	Self Help Skills						
6:00							
6:30		Church 6:30 - 7:30		Outside Activities weather Permits - inside Activities & Ride Participation			
7:00							
7:30				Refreshments			
8:00							
8:30	Bathing Personal Hygiene Skills						
9:00							
9:30	TV - BED						
10:00							
9:30							

[illegible] 101.3-84

STUDENT ACTIVITIES SCHEDULE

No.: 2293

Client: Thompson Susan

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
5:30	Bed						
6:00	Get up & dress						
6:30	Combing Hair						
7:00	Breakfast						
7:30	Tooth brushing						
8:00							
8:30	Prepare for Daily activities					Cottage Chores	
9:00	OT		OT		OT		
9:30	Speech Therapy		Speech Therapy		Speech Therapy	Cartoons	
10:00	Physical Therapy						
10:30	School class #28 10:30 - 11:30 (Mon - Fri)						
11:00							
11:30	Lunch						
12:00	Oral Hygiene Skills						
12:30							
1:00	ART				ART	Movie	
1:30		Home making 1:30-2:15		Home making 1:30-2:15			
2:00							
2:30							
3:00							
3:30	Rec	Speech Therapy	Rec	Speech Therapy	Rec		
4:00							
4:30	Personal Hygiene & Prepare for Supper						
5:00	SUPPER						
5:30	Self Help Skills						
6:00				cultural activities, watching Programs, Inside activities & Aide participation			
6:30							
7:00							
7:30				Refreshments.			
8:00	Bathing - Personal - Hygiene Skills						
8:30							
9:00	Television - BED						
9:30							
10:00							
10:30							

OR 301.3-04

JCAH

Joint Commission on Accreditation of Hospitals
875 North Michigan Avenue
Chicago, Illinois 60611
312/642-6061

John E. Affeldt, MD
President

July 20, 1984

RECEIVED
JUL 30 1984
DIRECTOR'S OFFICE
YRPH

Walter Kenzie
Chief Executive Officer
Ypsilanti Regional Psychiatric Hospital
3501 Willis Road
Ypsilanti, Michigan 48197

Dear Mr. Kenzie:

The Accreditation Committee of the JCAH Board of Commissioners is pleased to award your hospital's adult psychiatric program accreditation as a result of your survey. This accreditation is contingent upon a focused survey visit described in the enclosed Survey Report.

A list of recommendations is enclosed which should be considered your objectives and should be put into effect prior to the next survey. Except as required by law, this report is confidential on the part of JCAH; the further release of its content is a matter for your consideration and decision.

As a condition of accreditation, your organization will be required to conduct an interim self-survey approximately eighteen months from the date of your last full survey. At the appropriate time JCAH will send you the necessary forms and instructions. As a further condition of accreditation, you are required to notify JCAH of any changes in ownership and delivery of patient services as contained in the General Administrative Policies and Procedures Section of Consolidated Standards Manual for Child, Adolescent, and Adult Psychiatric, Alcoholism and Drug Abuse Facilities.

As an accredited organization, you are entitled to display a Certificate of Accreditation. Please complete and return the enclosed form to the JCAH Certificate Coordinator to assure that your Certificate is accurately prepared. This Certificate will be forwarded to you four to six weeks from receipt of this form. The Certificate of Accreditation and all copies remain the property of JCAH and must be returned if your organization is issued a new certificate reflecting a change in name or if accreditation expires or is withdrawn or revised for any cause.

Thank you for your support of and participation in voluntary accreditation.

Sincerely,

Myrene McAninch, Ph.D.
Director
Accreditation Program for
Psychiatric Facilities

cc: James Dawson, M.D., Head of the Professional Staff
C. Patrick Babcock, Chairman of the Governing Boy

Member Organizations
American College of Physicians
American College of Surgeons
American Dental Association
American Hospital Association
American Medical Association

YPSILANTI REGIONAL PSYCHIATRIC HOSPITAL
YPSILANTI, MICHIGAN

DATES OF SURVEY
May 21 - 24, 1984

SURVEYORS
Weaver O. Howard, M.D.
John Harden, M.H.A.
Janice Rabalais, R.N.

ACCREDITATION DECISION: Your hospital's adult psychiatric program has received a three-year accreditation contingent upon compliance with the recommendations in this report preceded by the symbol (C). These recommendations are summarized below for your convenience.

1. Insufficient registered nurses and activity therapists are provided to meet patient needs.
2. Underutilization, overutilization, and inefficient scheduling of the hospital's resources are not adequately addressed.
3. The written plan for evaluating the hospital's attainment of its goals and objectives is not inclusive of all identified goals and objectives.
4. Treatment plans do not include specific goals based upon assessments and all services available.
5. The written policies and procedures for the use of special treatment procedures are incomplete.

Failure to achieve compliance with the recommendations preceded by the symbol (C) may jeopardize your accreditation status.

CONTINGENCY: A focused survey will be scheduled approximately nine (9) months from the date of the Accreditation Committee meeting of July 20, 1984. This visit will be conducted by a physician surveyor for two days and will address only the recommendations on the following pages preceded by the symbol (C). In addition, the recommendations preceded by the symbol (+) should be given a high priority and must be in compliance prior to the next full survey.

The hospital will be notified of the date of this focused survey visit.

ACCREDITATION COMMITTEE ACTION: The results of this visit will be presented to the Accreditation Committee. The Accreditation Committee will consider the results of the survey and may remove or modify the contingency or, in the event that the hospital's progress is not acceptable, the hospital will be contacted regarding a tentative non-accreditation decision. The hospital will be notified by letter of the committee's decision.

YPSILANTI REGIONAL PSYCHIATRIC HOSPITAL
YPSILANTI, MICHIGAN
Page 2

ACCREDITATION PROGRAM FOR PSYCHIATRIC FACILITIES

RECOMMENDATIONS FOR FUTURE COMPLIANCE

WRITTEN PLAN FOR PROFESSIONAL SERVICES AND STAFF COMPOSITION

(C) 1. Within the scope of its activities, the facility shall have enough appropriately qualified health care professional, administrative, and support staff available to adequately assess and address the identified clinical needs of patients. (4.2)

SURVEYOR COMMENT: ADDITIONAL REGISTERED NURSES AND ACTIVITY THERAPISTS ARE NEEDED, AS EVIDENCED BY PATIENT INACTIVITY AND THE OVERUTILIZATION OF SECLUSION.

(C) 2. Inpatient programs shall have a registered nurse on duty at all times to plan, assign, supervise, and evaluate nursing care and to provide for the delivery of nursing care to patients. (4.3.2)

PERSONNEL POLICIES AND PROCEDURES

1. The personnel policies and procedures shall describe methods and procedures for supervising all personnel, including volunteers. (5.7)

SURVEYOR COMMENT: THE PERSONNEL POLICIES AND PROCEDURES DO NOT DESCRIBE THE METHODS AND PROCEDURES FOR SUPERVISING ALL PERSONNEL.

2. The policies and procedures shall include a mechanism for determining that all personnel are medically and emotionally capable of performing assigned tasks and are free of communicable and infectious diseases. (5.8)

SURVEYOR COMMENT: THE PERSONNEL POLICIES AND PROCEDURES DO NOT INCLUDE SUCH A MECHANISM.

3. The personnel service shall prepare an annual written statistical report concerning its functions. (5.17)

SURVEYOR COMMENT: SPECIFIC REFERENCE IS MADE TO THE LACK OF AN ANNUAL WRITTEN STATISTICAL REPORT CONCERNING THE FUNCTIONS OF THE PERSONNEL SERVICE.

FACILITY AND PROGRAM EVALUATION

(C) 1. The facility shall have a written plan for evaluating its progress in attaining its goals and objectives. (8.1.4)

SURVEYOR COMMENT: THE WRITTEN PLAN FOR EVALUATING THE FACILITY'S PROGRESS IN ATTAINING ITS GOALS AND OBJECTIVES IS NOT INCLUSIVE OF ALL IDENTIFIED GOALS AND OBJECTIVES.

(C) 2. The written plan shall specify when evaluations shall be conducted. (8.1.4.1)

SURVEYOR COMMENT: THE WRITTEN PLAN DOES NOT SPECIFY WHEN EVALUATIONS ARE TO BE CONDUCTED FOR ALL IDENTIFIED GOALS AND OBJECTIVES.

(C) 3. The written plan shall specify the information to be collected and the procedures for retrieving and analyzing this information. (8.1.4.2)

SURVEYOR COMMENT: THE WRITTEN PLAN DOES NOT SPECIFY THE INFORMATION TO BE COLLECTED AND THE PROCEDURES FOR RETRIEVING AND ANALYZING THIS INFORMATION.

(C) 4. There shall be documentation that the goals and objectives of facility, service, and programmatic activities shall be evaluated at least annually and revised as necessary. (8.1.5)

SURVEYOR COMMENT: STANDARDS 8.1.5 - 8.2 HAVE NOT BEEN ADDRESSED.

(C) 5. There shall be an explanation of any failure to achieve goals and objectives. (8.1.5.1)

(C) 6. There shall be documentation that the results of the evaluation shall be provided to the governing body and facility administration and shall be made available to staff. (8.1.5.2)

(C) 7. There shall be documentation that the findings of the evaluation have influenced facility and program planning. (8.2)

QUALITY ASSURANCE

(C) 1. The quality assurance program shall be reappraised at least annually through designated mechanisms. (9.6)

SURVEYOR COMMENT FOR STANDARDS 9.6 - 9.6.2: THE QUALITY ASSURANCE PROGRAM HAS NOT BEEN IN EXISTENCE FOR ONE YEAR.

(+) 2. The reappraisal should identify components of the quality assurance program that need to be instituted, altered, or deleted. (9.6.1)

(+) 3. Resultant recommendations, when instituted, should assure that the program is ongoing, comprehensive, effective in improving patient care and clinical performance, and conducted with cost-efficiency. (9.6.2)

4. Written criteria that relate to the essential or critical aspects of patient care and that are generally acceptable to the professional staff shall be used to assess problems and measure compliance with achievable goals. (9.7.2.3)

SURVEYOR COMMENT: THE CRITERIA FOR PROBLEM IDENTIFICATION NEED TO BE EXPANDED.

(+) 5. Periodic monitoring of the results of the corrective actions taken shall be conducted to assure that the identified problem has been eliminated or satisfactorily reduced. (9.7.4)

SURVEYOR COMMENT: MONITORING OF PROBLEM RESOLUTION DOES NOT INCLUDE ALL IDENTIFIED PROBLEMS.

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UTILIZATION REVIEW

(C) 1. In striving to provide optimal achievable patient care in a cost affective manner, the utilization review program shall make every effort to appropriately allocate facility resources. (10.2)

SURVEYOR COMMENT: THERE IS INSUFFICIENT EVIDENCE OF ONGOING AND ADEQUATE REVIEW OF ALLOCATION OF HOSPITAL RESOURCES.

(C) 2. The utilization review program shall address underutilization, overutilization, and inefficient scheduling of the facility's resources. (10.2.1)

SURVEYOR COMMENT: UNDERUTILIZATION, OVERUTILIZATION, AND INEFFICIENT SCHEDULING OF THE HOSPITAL'S RESOURCES ARE NOT ADEQUATELY REVIEWED.

(C) 3. The methods for identifying utilization-related problems shall include analysis of the appropriateness and clinical necessity of admission, continued stays, and supportive services; analysis of delays in the provision of supportive services; and examination of the findings of related quality assurance activities and other current relevant documentation. (10.4)

(C) 4. The facility's utilization review program, including the written plan, criteria, and length-of-stay norms, shall be reviewed and evaluated at least annually and revised as necessary to reflect the findings of the program's activities. (10.8)

SURVEYOR COMMENT: THE UTILIZATION REVIEW PROGRAM HAS NOT BEEN IN OPERATION FOR ONE YEAR.

STAFF GROWTH AND DEVELOPMENT

1. Orientation programs for new employees shall include event training or incident training, when appropriate, and shall familiarize each employee with existing staff backup and support systems. (12.4.2)

SURVEYOR COMMENT: EVENT/INCIDENT TRAINING IS NOT INCLUDED IN THE ORIENTATION PROGRAM FOR PROFESSIONAL AND SUPPORT STAFF.

INTAKE

1. During the intake process, every effort shall be made to assure that applicants understand the following:

   a. the rights and responsibilities of patients, including the rules governing patient conduct and the types of infractions that can result in disciplinary action or discharge from the facility. (16.7)

SURVEYOR COMMENT: SPECIFIC REFERENCE IS MADE TO THE LACK OF EVIDENCE THAT PATIENT RIGHTS ARE REVIEWED WITH THE PATIENT ON ADMISSION.

TREATMENT PLANS

(C) 1. The treatment plan shall contain specific goals that the patient must achieve to attain, maintain, and/or reestablish emotional and/or physical health as well as maximum growth and adaptive capabilities. (18.1.9)

SURVEYOR COMMENT: STATED TREATMENT GOALS ARE ACTUALLY OBJECTIVES RELATED TO THE TREATMENT PROCESS.

(C) 2. These goals shall be based on assessments of the patient and, as appropriate, the patient's family. (18.1.9.1)

(C) 3. The treatment plan shall describe the services, activities, and programs planned for the patient and shall specify the staff members assigned to work with the patient. (18.1.11)

SURVEYOR COMMENT: SPECIFIC REFERENCE IS MADE TO ACTIVITY SERVICES, WHICH ARE NOT INCLUDED IN TREATMENT PLANS.

(C) 4. When appropriate, the patient shall participate in the development of his or her treatment plan, and such participation shall be documented in the patient's record. (18.1.14)

SURVEYOR COMMENT: SPECIFIC REFERENCE IS MADE TO THE LACK OF EVIDENCE OF THE PATIENT'S PARTICIPATION IN TREATMENT PLANNING.

SPECIAL TREATMENT PROCEDURES

(C) 1. Treatment procedures that require special justification shall include, but not necessarily be limited to, the use of restraint and seclusion. (19.1)

SURVEYOR COMMENT: METAL CHAIRS WITH TRAYS FASTENED ACROSS THE SEAT, WHICH WERE ORIGINALLY USED TO FEED PHYSICALLY HANDICAPPED PATIENTS, ARE NOW USED FOR PURPOSES OF RESTRAINT. PATIENTS ARE PLACED IN THESE CHAIRS WITH THEIR HANDS TIED OR PLACED IN CAMISOLES. ADDITIONALLY, SECLUSION IS OVERUSED BY STAFF.

(C) 2. The facility shall have written policies and procedures that govern the use of restraint or seclusion. (19.2)

SURVEYOR COMMENT: SPECIFIC REFERENCE IS MADE TO THE NEED TO ADDRESS THE USE OF THE AFOREMENTIONED CHAIR IN THE SPECIAL TREATMENT POLICIES AND PROCEDURES.

(C) 3. The clinical indications for the use of special treatment procedures shall be documented in the patient's record. (19.1.4)

SURVEYOR COMMENT: SPECIFIC REFERENCE IS MADE TO INADEQUATE DOCUMENTATION OF THE CLINICAL INDICATIONS FOR THE USE OF SPECIAL TREATMENT PROCEDURES.

(C) 4. Each written order for restraint or seclusion shall be time-limited and shall not exceed 24 hours. (19.2.3)

(C) 5. Staff who implement written orders for restraint or seclusion shall have documented training in the proper use of the procedure for which the order was written. (19.2.8)

SURVEYOR COMMENT: SPECIFIC REFERENCE MADE TO THE LACK OF DOCUMENTED TRAINING IN THE USE OF RESTRAINT OR SECLUSION.

PHARMACEUTICAL SERVICES

1. There shall be methods of detecting drug side effects or toxic reactions. (26.15)

SURVEYOR COMMENT: METHODS FOR DETECTING DRUG SIDE EFFECTS OR TOXIC REACTIONS HAVE NOT BEEN DEVELOPED.

REHABILITATION SERVICES
ACTIVITY SERVICES

1. Inpatient, residential, and partial-day facilities shall provide, or make arrangements for the provision of, activity services to meet the physical, social, cultural, recreational, health maintenance, and rehabilitation needs of patients. Activity services involve the principles and practices of art, dance, movement, music, occupational therapy, recreational therapy, and many other disciplines. (30.1)

SURVEYOR COMMENT: THE ACTIVITY PROGRAM IS NOT DESIGNED TO MEET THE NEEDS OF PATIENTS, E.G., MUSIC, DANCE, MOVEMENT, AND OCCUPATIONAL THERAPY.

2. Appropriate activities shall be provided to all patients during the day, in the evening, and on the weekend. (30.5)

SURVEYOR COMMENT: ACTIVITIES APPEAR TO BE UNDERUTILIZED BY PATIENTS, AND ARE INAPPROPRIATE TO THE TYPE OF UNITS OR TYPE OF PROGRAM, E.G., OFF-GROUNDS BOWLING ON ADMISSION UNITS.

3. Whenever possible, patients should participate in planning activity services. (30.5.2)

SURVEYOR COMMENT: DOCUMENTATION THAT PATIENTS ARE INVOLVED IN PLANNING ACTIVITY SERVICES IS ABSENT.

4. The activities program shall be reviewed and revised according to the changing needs of patients. (30.5.4)

SURVEYOR COMMENT: THE ACTIVITIES PROGRAM IS NOT REVISED ACCORDING TO THE CHANGING NEEDS OF PATIENTS.

5. When indicated, activity services shall be incorporated in the patient's treatment plan. (30.6)

SURVEYOR COMMENT: ACTIVITY SERVICES ARE NOT INCORPORATED INTO TREATMENT PLANS.

6. Activity services that are included in a patient's treatment plan shall reflect an assessment of the patient's needs, interests, life experiences, capacities, and deficiencies. (30.6.1)

7. Activity service staff shall collaborate with other professional staff in delineating goals for patients' treatment, health maintenance, and vocational adjustment. (30.6.2)

8. The patient's record shall contain progress notes that describe the patient's response to activity services, as well as other pertinent observations. (30.6.3)

9. Activity service staff shall be sufficient in number and skills to meet the needs of the patients and to achieve the goals of the service. (30.10)

BUILDING AND GROUNDS SAFETY

(+) 1. Approved smoke dampers shall be provided in duct penetrations of smokestop partitions. These dampers shall be activated by a local smoke detector. (NFPA - 101: 12 - 3.7.9, 13 - 3.7.7, 6-3)

2. There shall be two remote approved exits on each floor or fire section of the building. (NFPA - 101: 12 - 2.4.1, 13 - 2.4.1)

SURVEYOR COMMENT: STAIR TOWERS ARE CURRENTLY UNDER CONSTRUCTION.

FUNCTIONAL SAFETY AND SANITATION

1. Written records shall be maintained of all inspections performed, including any actions taken or recommended. (32.3.2)

SURVEYOR COMMENT: SPECIFIC REFERENCE IS MADE TO ELECTRICAL POWER DISTRIBUTION SYSTEMS.

2. Nonclinical equipment shall be inspected and tested at regular intervals to be determined by the chief of the engineering/maintenance department, and the results shall be recorded. (32.5)

THERAPEUTIC ENVIRONMENT

(+) 1. Ventilation shall be sufficient to remove undesirable odors. (33.7.2)

SURVEYOR COMMENT: SEVERAL MEN'S WASHROOMS AND DORMS HAVE A STRONG URINE ORDOR.

(+) 2. All areas and surfaces shall be free of undesirable odors. (33.8)

SURVEYOR COMMENT: SPECIFIC REFERENCE IS MADE TO THE MEN'S WASHROOMS AND DORMS.

(+) 3. Door locks and other structural restraints should be used minimally. (33.9)

SURVEYOR COMMENT: PATIENT ROOMS AND DORMS ARE KEPT LOCKED TO PREVENT ACCESS.

(+) 4. The use of door locks or closed sections shall be approved by the professional staff and the governing body. (33.9.1)

(+) 5. Furnishings shall be clean and in good repair. (33.12.1)

SURVEYOR COMMENT: SPECIFIC REFERENCE IS MADE TO A LARGE NUMBER OF BROKEN FURNISHINGS.

(+) 6. Broken furnishings and equipment shall be repaired promptly. (33.12.4)

SURVEYOR COMMENT: SPECIFIC REFERENCE IS MADE TO THE ACTIVITY CENTER.

HOSPITAL-SPONSORED AMBULATORY CARE SERVICES

1. The facility shall have written policies and procedures for maintaining a clean and safe environment. (34.1)

SURVEYOR COMMENT: SPECIFIC REFERENCE IS MADE TO THE LACK OF WRITTEN POLICIES AND PROCEDURES FOR THE LODGE PROGRAM.

STERILE SUPPLIES AND EQUIPMENT

1. The policies and procedures should relate to, but not be limited to, the following:

   a. the cleaning and sanitizing of work spaces used in the preparation of sterile supplies. (36.2)

SURVEYOR COMMENT: THE POLICIES AND PROCEDURES DO NOT INCLUDE IDENTIFICATION OF AREAS WHERE CONTAMINATED INSTRUMENTS OR ITEMS ARE TO BE PLACED, WHERE INSTRUMENTS ARE TO BE CLEANED AND WRAPPED, AND HOW COUNTER SPACE USED FOR WRAPPING INSTRUMENTS IS TO BE CLEANED.

******

an

U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General

Washington, D.C. 20530

FEB 19 1985

CERTIFIED MAIL - Return Receipt Requested

Honorable James J. Blanchard
Governor of Michigan
Executive Office
Capitol Building
Lansing, Michigan 48909

Re: Investigation of Ypsilanti Regional Psychiatric Hospital

Dear Governor Blanchard:

On November 18, 1983, we informed you of our intention to investigate conditions at Ypsilanti Regional Psychiatric Hospital (YRPH), in Ypsilanti, Michigan, pursuant to the Civil Rights of Institutionalized Persons Act, 42 U.S.C. § 1997. We are now writing to notify you of the factual findings of our investigation, the nature of the constitutional deficiencies found at YRPH, and the minimum remedial measures necessary to address these violations.

Our investigation included expert tours of the facility by three different consultants. These consultants and Department of Justice attorneys had extensive interviews with YRPH administrators, and professional and direct care staff. A considerable amount of time was also devoted to interviewing patients and examining numerous patient charts. Finally, our investigation included a review of such documentation as YRPH staffing figures, hospital and Department of Mental Health policies and procedures, mortality reviews, incident reports, seclusion and restraint statistics, training programs and manuals, hospital surveys, and internal medical care evaluation studies. Throughout our investigation YRPH staff, as well as representatives from the Department of Mental Health and the Attorney General's Office, were extremely cooperative and provided us with great assistance.

YRPH has undergone many physical changes in recent months in its successful effort to obtain accreditation by the Joint Commission on Accreditation of Hospitals (JCAH). We commend YRPH's efforts in this regard, yet our consultants found that there remain several areas in need of immediate attention in order to ensure that conditions at Ypsilanti Regional Psychiatric Hospital meet constitutional requirements.

1. Staffing

There is an insufficient number of both professional and direct care staff to provide adequate medical care and that degree of treatment necessary to avoid undue risks to the personal safety of YRPH patients and insure freedom from undue bodily restraint. The number of qualified psychiatrists and medical doctors is severely lacking. Six recently vacated psychiatrist positions, representing approximately 25% of the previous total staff, remain unfilled. One psychiatrist is assigned to two or three wards, responsible for the treatment of up to 80 patients. Due to an inadequate number of psychiatrists, patients who are violent, self-abusive or otherwise dangerous receive no treatment to ensure their reasonable safety. Too often they are simply placed in seclusion or restraint to control their behavior. Additional professional staff members are thus necessary in order to provide such residents with treatment programs designed to reduce or eliminate the use of bodily restraints.

The deficiency in the number of medical doctors at YRPH constitutes an immediate risk of harm to patients' health and safety. With only two full-time and two half-time medical doctors on staff, patients are subject to a host of practices which represent substantial departures from acceptable medical practices, e.g., diagnoses absent justification, medication inconsistent with accepted medical judgment, and dangerous delays in receiving medical treatment for serious injuries.

A staff of seven psychologists must provide care and treatment to over 650 patients at YRPH. Their responsibilities include making diagnostic assessments, administering psychological tests, and conducting therapy programs necessary to protect patients' liberty interests. Because of the small number of psychologists, the above tasks are not carried out for many patients at YRPH, which means that treatment decisions in reliance on the above tasks, are often made absent the exercise of professional judgments by qualified professional staff.

One of the most severe professional staff shortages is in nursing. According to one of the YRPH administrators there are too few registered nurses to dispense medications and carry out appropriate medical procedures. It is common on the afternoon and night shifts for one RN to be responsible for a whole building, each building containing five or more wards, and over 200 patients. With such a heavy patient load, most procedures ordinarily carried out by RN's are instead carried out by resident care aides (RCAs) - attendant care staff. In addition to providing direct patient care appropriate to their level of training, RCAs must also perform such tasks as administering medications, carrying out medical procedures and making medical judgments, although they lack the qualifications, training and experience necessary to perform such tasks. Due to the insufficient number of RN's, RCAs carry out these responsibilities with inadequate and on some shifts no supervision by qualified medical staff. This substantial departure from accepted medical practice subjects patients to unreasonable risks of harm to their personal safety, such as hazardous medical procedures, excessive use of seclusion and restraint, and inappropriate medication. Our consultants have reached this conclusion based upon a review of patients' medical charts, incident reports, and staff interviews.

Because of the above staff shortages, YRPH patients frequently receive inadequate care by unqualified, untrained and inexperienced staff. In that treatment decisions are often made absent the exercise of professional judgments by qualified medical staff, YRPH patients fail to receive adequate medical care, suffer physical harm and fail to receive that degree of treatment necessary to avoid undue risks to personal safety and avoid undue bodily restraint.

2. Medical and Administrative Practices

YRPH's medical, psychopharmacological and related administrative recordkeeping practices represent significant departures from accepted professional medical judgment, and thereby subject patients to unreasonable risks of harm to their personal safety. While the coprescription of two or more drugs at one time may be valid in some circumstances, in

22% of the charts reviewed by one of our consultants, instances of improper polypharmacy practices were found at YRPH. The prevalence of this practice suggests that there is a great deal of medication being administered at YRPH absent the exercise of professional judgment. Lithium, an antidepressant, and antipsychotic agents were often coprescribed with little documentation to justify this practice. Antiparkinson agents were prescribed without justification leading to unnecessary side effects. Our consultants found that these practices also increase the likelihood of drug interactions, and often counteract the therapeutic effect achieved by either drug alone. The above examples violate the State's own medical standard guidelines and represent a substantial departure from accepted medical practice, with the result that YRPH patients are subject to unreasonable risks of harm to their personal safety.

Our consultants also found that medication orders were not reviewed within any acceptable and appropriate time period. YRPH's across the board policy of reviewing medication orders every 30 days fails to distinguish between chronic patients, for whom it may be reasonable to prescribe long term medication, and acute patients, whose drug needs must be reviewed more frequently to accommodate their changing clinical status. YRPH's present practice leads to inappropriate medication, overmedication, and unnecessary side effects due to the failure of YRPH professionals to exercise timely judgments with respect to the administration of psychotropic medication.

The administration of medication to YRPH patients represents a grave area of constitutional concern. In light of the nursing shortage discussed above, RCAs often administer medication with inadequate or nonexistent supervision by professional care staff, e.g., nurses, particularly on the night shifts. Many times it is left to the discretion of RCAs as to when to administer pro re nata (PRN), as needed, medication orders. Yet the RCAs' backgrounds do not sufficiently equip them to deal with the variety of clinical situations which may arise in administering antipsychotic agents or in recognizing the onset of side effects. Thus, important medical treatment decisions are being made in the absence of the exercise of professional judgment by qualified physicians and RN's. This practice leads to medical error, prolonged hospital stays, an increased number of incidents resulting from aggressive and often violent behavior and damaging side effects, thereby placing patients in unreasonable jeopardy of physical harm.

Medical monitoring is another crucial aspect of patient care which fails to meet accepted standards of medical practice at YRPH. In many instances our consultants found that appropriate tests and studies related to a patient's medical status were either not ordered or not reevaluated. Blood levels were often not taken where medically indicated to determine toxicity or, where appropriate, a patient's progress with particular medications. In more than 15% of the patients' charts reviewed by one consultant, deficiencies were found in medical monitoring, a process which is extremely important for patients who receive medication for long periods of time and are at risk for such drug induced diseases as tardive dyskinesia (TD). YRPH's practices in this regard represent substantial departures from accepted medical judgment.

Additionally, YRPH fails to complete screening and follow-up assessments related to drug side effects, particularly tardive dyskinesia (TD), a side effect resulting from long term use of antipsychotic drugs. ~~Appropriate medical procedures to prevent side effects from becoming irreversible are not carried out.~~ Such practices are contrary to accepted medical judgment and subject patients to unreasonable risks of harm.

Recordkeeping practices present another area of deficiency at YRPH. In interviewing patients and reviewing their charts, our consultants found several examples of diagnoses for which there were no discernable clinical basis. Diagnostic symptoms were often not noted on the patients' records. Our consultants found that medication was frequently prescribed and changed without rationale in the patients' charts. Multiple potent psychotropic agents were administered without noting the justification in the patients' records. PRN medications were dispensed without physicians' orders indicating the behavior necessitating their use, and without documentation in the patients' charts as to the reason for their actual use. Progress notes on side effects assessments were lacking, and criteria used to establish each psychiatric diagnosis were generally not documented in the charts reviewed by our consultants. In light of the inadequate recordkeeping practices at YRPH it is impossible for qualified professionals to make medically appropriate and reasonably safe treatment decisions. It therefore represents a substantial departure from accepted medical judgment and subjects patients at YRPH to unreasonable risks of harm.

3. Seclusion and Restraint

Seclusion and restraint are often used without doctors' orders, RN notes, documentation as to why a person was secluded or restrained and how long he or she remained there, as well as appropriate observations to determine not only patient progress and safety, but whether adequate justification exists to keep the patient secluded or restrained.

YRPH does not provide residents treatment programs designed to eliminate or reduce the need for bodily restraint. Accordingly, behavioral problems are commonly dealt with by placing the patient in seclusion or restraints for the convenience of staff in lieu of necessary treatment. */ Ward staff also often use seclusion and restraint as a means of punishment. Once patients are placed in seclusion or restraint, close supervision by professional staff is nonexistent. Our consultants concluded that staffing deficiencies contribute to YRPH's failure to provide patients with necessary training programs and thus to the concomitant improper use of seclusion and restraint.

4. Protection from Harm

A review of incident reports dating from July, 1983 to March, 1984, supports the above findings. Such incidents include patient on patient, patient on staff, and staff on patient abuse, as well as inappropriate seclusion practices and unprofessional judgements made by attendant care staff. The likelihood of harm suffered by patients is increased because of YRPH's staffing deficiencies, questionable psychopharmacological practices, unjustified use of seclusion and restraint, and the absence of medically acceptable psychiatric treatment programs necessary to avoid undue risks to personal safety and insure freedom from undue bodily restraint. Unless substantial improvement is made in all of the areas focused on above, conditions at YRPH will remain in violation of the United States Constitution.

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*/ Hospital records covering a recent one year period showed 7,210 incidents of seclusion, and 2,730 episodes of restraint. YRPH statistics showed that a relatively small group of individuals were subject to these practices each month. One patient was put in seclusion 17 times in two months, primarily for talking about voices that he heard, in addition to periodic aggressive behavior.

Minimum Remedial Measures

The above conditions threaten the health and safety of patients at YRPH. Measures must be taken to bring each of these conditions to the minimum level required by the Constitution of the United States. To this end, it is necessary to enter with the State of Michigan into a legally binding and judicially enforceable agreement to rectify the deficiencies described above and ensure that constitutionally adequate conditions are maintained thereafter. We suggest that the following measures would represent significant progress at YRPH:

1. Hiring sufficient numbers of qualified psychiatrists, nurses, and other trained professional and direct care staff to ensure, on a continuing basis, that patients are provided with minimally adequate medical care and are not subjected to unreasonable risks of harm to their personal safety.

2. Development of a system through which the appropriateness and safety of patient medical care can be monitored by an experienced and qualified staff. In this regard the State should develop and enforce requirements for minimally adequate recordkeeping and for physician review and approval of assessments and decisions relating to medical care made by nonphysician staff.

3. Development and implementation of guidelines for the appropriate use of seclusion and restraint.

4. Treatment programs must be professionally designed for those residents for whom such treatment will reduce or eliminate unreasonable risks to their personal safety and/or the need for undue bodily restraint. Immediate attention must be given to residents with self-injurious, aggressive, and other destructive behaviors by identifying them and implementing necessary treatment programs.

5. Development and implementation of measures adequate to assure staff compliance with hospital policies, protocols, and standards of job performance and behavior relating to the areas discussed above.

I would note that many of our findings and recommendations will come as no suprise to YRPH personnel. Many of these individuals candidly acknowledged the existence of areas requiring improvement. It was clear to us that YRPH employs many conscientious and dedicated staff who strive to provide the best care possible. We would be remiss if we failed to commend these persons for their very substantial efforts.

Again, we want to thank you for your fine cooperation. Our attorneys will be contacting your office shortly to discuss this matter further. They will be able to provide your staff with further detailed information. We would also be happy to make our consultants available to help the State formulate a specific and detailed plan for effectuating a legally binding and judicially enforceable agreement with the United States in achieving constitutionally adequate conditions at YRPH. Information about federal financial assistance which may be available to assist with the remediation process can be obtained through the United States Department of Health and Human Services' Regional Office (Michelle Harris, Director, Intergovernmental and Congressional Affairs; (312) 353-5132) and through the United States Department of Education by contacting individuals listed in the attached information guide. I look forward to working with [illegible] in a spirit of full cooperation to resolve these matters expeditiously.

Sincerely,

Wm. Bradford Reynolds
Assistant Attorney General
Civil Rights Division

cc: Frank J. Kelley
Attorney General

C. Patrick Babcock
Director
Department of Mental Health

Walter Kenzie
Facility Director
Ypsilanti Regional Psychiatric Hospital

Leonard R. Gilman
United States Attorney

National Association of Private Residential Facilities for the Mentally Retarded

6269 Leesburg Pike, Suite B-5
Falls Church, Virginia 22044

Area Code 703 / 536-3311

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EXECUTIVE DIRECTOR:
Joni Fritz

April 1, 1985

Senator Lowell Weicker
303 Hart Building
Washington, D.C. 20510

Dear Senator Weicker:

We would like to submit for the record some more optimistic testimony than that which you are currently hearing during these three days of testimony on conditions experienced by people living in large institutions.

Accompanying me to Monday's hearing was Ms. Bonnie-Jean Brooks, Executive Director of Opportunity Housing in Bangor, Maine. Her agency is serving people who are dually diagnosed as having both mental retardation and mental illness. Most of her clients have lived in both types of institutions. (They will not accept clients who are easy to serve.)

Many of the people served by Opportunity Housing have few verbal skills. Some, however, can tell their own stories of sexual and physical abuse experienced while living in the institutions. Two of these people are described in the enclosed articles.

The article from our monthly newsletter, LINKS, recounts the exciting story of Edith Rackliff (now Braley), who has dramatically moved from the confines of a state mental hospital to her own home, which she shares with her husband Norman. I was fortunate enough to have been invited to have tea and homemade apple pie with the Braley's on a recent visit to Bangor. Their life in Bangor is quite different from that which they experienced in state institutions. Their home is modest, like many others in Bangor. Somehow they manage to survive on SSI. Outside aid which provides professional support the help them continue to live in the community is funded by the State of Maine. Jobs are hard to find in Maine, and the last to be hired are people like Edith and Norman who have lived in mental hospitals. Life isn't easy, but it is a joy to these people who have experienced institutional living.

This couple is testimony to the success which can be achieved when people are moved to the community by agencies which have faith in their ability to succeed. It can be quite costly to provide the intervention necessary to help people reach this high level of independence, but it can and is being done in those communities that are willing to work through the bad times to reach the day that these people are self-sufficient enough to be on their own. Treatment of this nature is cost-effective and far more humanistic than that which we have heard about in your hearing.

There are many agencies across the country which are succeeding in helping people lead more productive lives. As Senator Simon pointed out, these are usually privately operated facilities. Today many of them are able to access federal financial assistance to serve their clients. Of course, there are never enough resources to serve all of those who need help.

The people who operate these homes are usually too busy to write of their successes. Many of those being served are unable or unwilling to tell about their own experiences. John Stanley, who was interviewed for the Bangor Daily News article, and Edith Rackliff Braley are two who could personally share their stories with you.

Opportunity Housing is just one of thousands of agencies across the nation that help people lead more normal, productive lives. Few, however, are willing to serve such difficult clients. The transition from institution to community does not come easily for this population, and initially it is costly. Agencies like Opportunity Housing prove that it can be done.

We hope that the hearings you are conducting will result in federal programs which will facilitate the return to community life of all of our nation's citizens who have mental retardation or mental illness.

We will be glad to help you identify programs which, like Opportunity Housing, are demonstrating that community programs really work. Please don't hesitate to contact us when you are looking for some good programs that help people who are mentally retarded achieve a high level of self-dependence.

Sincerely,

Joni Fritz

Joni Fritz
Executive Director

cc: Senator Paul Simon

Senator **Weicker**. Tomorrow we will be hearing panels of witnesses from New Mexico, New York, California, Massachusetts, and Connecticut.

The hearing will commence at 9:30 in this room, and the subcommittees will stand in recess until that time.

[Whereupon, at 11:40 a.m., the subcommittees were recessed, to reconvene at 9:30 a.m., April 3, 1985.]

CARE OF INSTITUTIONALIZED MENTALLY DISABLED PERSONS

WEDNESDAY, APRIL 3, 1985

U.S. Senate, Subcommittee on the Handicapped, Committee on Labor and Human Resources, and Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Committee on Appropriations,

Washington, DC.

The subcommittees met, pursuant to recess, at 9:35 a.m., in room SR-428A, Russell Senate Office Building, Senator Lowell Weicker, Jr. (chairman of the subcommittees) presiding.

Present: Senators Weicker, Nickles, Kerry, and Simon.

OPENING STATEMENT OF SENATOR WEICKER

Senator Weicker. The subcommittees will come to order. First, I would like to acknowledge our signers, those who have interpreted the testimony in sign language. They are from the Gallaudet College interpreting services. On Monday we had Earl Elkins and Sheila Grinell, and yesterday and today we have Earl Elkins and Dee Davis. I think they have done an outstanding job, and I want to express my appreciation to them.

Second, I want to repeat the phone number and the address of the subcommittee for those who care to have testimony placed in the record. To date we have received 65 calls from people who want testimony placed in the record. That does not include those who want copies of the report, and those who are either complimentary or derogatory in their remarks, but specifically 65 persons who will be placing testimony in the record. And, I might add, that testimony will be carefully gone over by the staff, and staff could very well be contacting those individuals who submitted testimony.

So if anybody desires to do so, they should send their testimony to the U.S. Senate, Subcommittee on the Handicapped, 113 Hart Building, Washington, DC 20510. The telephone number of the subcommittee is area code (202) 224-6265.

I also want to acknowledge the helpfulness of the media, electronic and written, in giving exposure to these hearings. That is the only way we can crack through this wall of silence.

The people whom we have had testify before us were the result of some very fine work by my staff, but I am sure there are many more with their own stories to tell that we never knew existed. So I owe a special debt of thanks to the media that has attended these hearings.

I also had a letter sent to me last night from the U.S. Department of Justice:

> DEAR SENATOR WEICKER: I have had an opportunity to review the staff report on the institutionalized mentally disabled prepared at your request, and would appreciate if you would make the enclosed response a part of the hearing record.
>
> BRADFORD REYNOLDS,
> *Assistant Attorney General, Civil Rights Division.*

That will be made part of the record and also the opening statement of Senators Kennedy and Kerry.

[The statements and letter referred to follow:]

STATEMENT OF SENATOR EDWARD M. KENNEDY
BEFORE THE
SENATE SUBCOMMITTEE ON THE HANDICAPPED
APRIL 3, 1985

I wish to thank my distinguished colleague from Connecticutt, Senator Weicker, for holding these hearings which are uncovering the heinous conditions in which thousands of our country's citizens exist today. We now know that individuals in institutions for the mentally ill exist, they do not live. They exist from one minute to the next in fear for their safety and even their lives; they exist in pain; they are unnecessarily physically restrained; they are over medicated; and they exist in sub human conditions.

The Federal Government is at present one of the largest supporters of these facilities which perpetrate these violations on vulnerable children, adults and the elderly. Support for these conditions in any form is unconscionable.

The witnesses who have come before the SubCommittee to tell their stories should be commended. Their help and courage will make a difference for those who exist in these facitilites.

It is my hope that the product of these hearings will be legislative changes and initiatives that will provide a life for all individuals who are mentally ill, not merely an existence. It is my hope that all individuals in institutions for the mentally disabled will realize the fulfillment of their consitutional rights to life, liberty, and the pursuit of happiness and that these rights are realized in the most appropriate environment.

These individuals may not attain these rights on their own and so it is our moral obligation to provide them with the means to reach for these attainable goals. And I intend to work toward this end. I offer Senator Weicker my full commitment to working toward these goals in the days ahead.

OPENING STATEMENT
OF
SENATOR JOHN KERRY
BEFORE THE
SUBCOMMITTEE ON THE HANDICAPPED
COMMITTEE ON LABOR AND HUMAN RESOURCES
AND
SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES
COMMITTEE ON APPROPRIATIONS

APRIL 3, 1985

MR. CHAIRMAN:

I AM DELIGHTED TO BE PARTICIPATING IN THESE FIRST HEARINGS OF THE SUBCOMMITTEE ON THE HANDICAPPED IN THIS CONGRESS. THESE ARE ALSO THE FIRST HEARINGS IN A VERY LONG WHILE THAT WILL NOT BENEFIT FROM THE PARTICIPATION OF JENNINGS RANDOLPH WHO ABLY SERVED THE SUBCOMMITTEE AS ITS CHAIRMAN AND LATER AS ITS RANKING MINORITY MEMBER. I KNOW THAT HIS PRESENCE WILL BE MISSED BY THOSE WHO SERVED WITH HIM. AS HIS SUCCESSOR IN THAT POST, LET ME ASSURE THE SUBCOMMITTEE THAT I TOO WILL MISS SENATOR RANDOLPH'S WISDOM AND LEADERSHIP.

I WOULD ALSO LIKE TO COMMEND YOU MR. CHAIRMAN, FOR THE CONTINUING SERVICE YOUR LEADERSHIP HAS PROVIDED TO A PART OF OUR NATION THAT HAS FOR TOO LONG SUFFERED THE TREATMENT, AND STATUS AS SECOND CLASS CITIZENS. THE IMPACT THAT THESE HEARINGS HAVE HAD SO FAR HAS BEEN GREAT AND THEIR CONTINUANCE SHOULD PROVIDE EVEN MORE SUBSTANTIAL IMPROVEMENTS THROUGHOUT THE NATION'S INSTITUTIONS.

FORTUNATELY, IT APPEARS THAT SOME CHANGES IN THE STATUS QUO ARE FINALLY BEGINNING TO TAKE PLACE AND I BELIEVE THAT YOUR ENERGY AND VIGILANCE CONCERNING THIS ISSUE HAVE BEEN THE MOTIVATING FORCE FOR CHANGE.

I HAVE FOLLOWED THE HISTORY OF THESE HEARINGS AND MOST RECENTLY AS LIEUTENANT GOVERNOR OF MASSACHUSETTS, I OBSERVED THE PROBLEMS FROM A STATE PERSPECTIVE. AND WHILE I HAVE NO INTENTION OF BEING AN APOLOGIST FOR STATE GOVERNMENTS THAT HAVE IN MANY CASES BEEN WOEFULLY INADEQUATE IF NOT IRRESPONSIBLE IN THEIR RESPONSE TO THESE ISSUES, I AM SENSITIVE TO THE MANY PROBLEMS STATES HAVE HAD DEALING WITH THE FEDERAL GOVERNMENT. THERE IS NO QUESTION THAT STATE INSTITUTIONS AROUND THIS COUNTRY ARE DISGRACEFUL AS WE HAVE HEARD DURING THE PAST DAYS OF THESE HEARINGS. I HOPE THAT THE INTRODUCTION OF THIS EVIDENCE INTO THE CONSCIOUSNESS OF THE SENATE AND THE AMERICAN PEOPLE WILL HELP END THIS TRAVESTY THAT WE SEE SO OFTEN IN INSTITUTIONAL CARE ACROSS AMERICA.

ALREADY IN MY OWN STATE OF MASSACHUSETTS WE HAVE SEEN SOME BREAKTHROUGHS. THE STATE HAS UNDERGONE EXTENSIVE DEINSTITUTIONALIZATION. TWENTY YEARS AGO THE STATE HOUSED APPROXIMATELY 20,000 INDIVIDUALS IN THIRTEEN STATE MENTAL HOSPITALS. TODAY THERE ARE ROUGHLY 2,200 IN SEVEN STATE HOSPITALS. THIS SHIFT HAS BEEN ACCOMPANIED BY THE CREATION OF CONGREGATE HOMES AND COMMUNITY LIVING PROJECTS WHICH ARE OPERATED UNDER A MEDICAID WAIVER. HOWEVER, WHILE THESE PROGRAMS ARE GOOD, THEY BARELY TOUCH THE TIP OF THE ICEBERG. UNDOUBTABLY, IN PLANNING DEINSTITUTIONALIZATION WE MUST FOCUS ON TWO THINGS: FIRST, THOSE INDIVIDUALS WHO ARE DEINSTITUTIONALIZED MUST BE HOUSED IN THE PROPER SETTINGS

THAT BEST FIT THEIR NEEDS. SECONDLY, ANY FURTHER DEINSTITUTIONALIZATION MUST BE ACCOMPANIED BY CAREFUL CONSIDERATION FOR THE TREATMENT GIVEN TO ACUTE MENTALLY ILL PATIENTS WHO REQUIRE INTENSIVE 24-HOUR CARE. OUR INSTITUTIONS HAVE PROBLEMS. WE STILL HAVE CHILDREN HOUSED IN ADULT WARDS, AND SOME STATE HOSPITALS THAT ARE UNDERGOING MAJOR INVESTIGATIONS FOR GRUESOME ABUSES. OUR STATE INSTITUTIONS IN MASSACHUSETTS STILL HAVE A LONG ROAD TO TRAVEL AND I KNOW FROM FIRSTHAND EXPERIENCE THAT THE STATE IS WORKING IN THE CORRECT DIRECTION. THERE IS WITHOUT A DOUBT A SIGNIFICANT NEED FOR IMPROVED MANAGEMENT AND ADDITIONAL COMMUNITY LIVING ARRANGEMENTS.

THIS WEEK WE HAVE HEARD FROM THOSE CLOSEST TO THE PROBLEMS -- THE PATIENTS, PROVIDERS, PARENTS AND ADVOCATES WHO OBSERVE INSTITUTIONAL ABUSE ON A DAILY BASIS. IT IS MY HOPE THAT THEIR COURAGE TO COME AND TESTIFY BEFORE OUR COMMITTEE WILL SERVE TO ENLIGHTEN THE SENATE AND GIVE THE COMMITTEE THE ASSISTANCE IT NEEDS TO ADDRESS THE APPALLING SITUATION IN OUR INSTITUTIONS WITH REALISTIC AND DOABLE SOLUTIONS.

I LOOK FORWARD TO TODAY'S HEARINGS AND HOPE THAT WE WILL HEAR PROPOSALS THAT CAN GIVE US A NEW DIRECTION.

U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General *Washington, D.C. 20530*

April 2, 1985

Honorable Lowell P. Weicker, Jr.
United States Senate
313 Russell Senate Office Building
Washington, D. C. 20510

Dear Senator Weicker:

I have had an opportunity to review the "Staff Report on the Institutionalized Mentally Disabled" prepared at your request and would appreciate it if you would make the enclosed response a part of the hearing record.

Sincerely,

Wm. Bradford Reynolds
Assistant Attorney General
Civil Rights Division

Attachment

cc: Members of the Subcommittee on the Handicapped, Committee on Labor and Human Resource

Members of the Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Committee on Appropriations

RESPONSE TO SENATE SUBCOMMITTEE'S REPORT

The Senate Subcommittee on the Handicapped has issued a 246 page "Staff Report on the Institutionalized Mentally Disabled". Thirty-four pages of that Report are devoted to the enforcement activities of the Department of Justice under the Civil Rights of Institutionalized Persons Act (CRIPA). We believe the Report's discussion of our activities is unbalanced, factually inaccurate and plainly unfair.

Before addressing the specific inaccuracies in the Report, I believe it is important to reiterate that the Department's objective under CRIPA is to provide relief required under the Act to the greatest number of people in the shortest period of time. CRIPA requires that, before the Attorney General can bring a civil action, he must have reasonable cause to believe that the conditions of confinement (1) are "flagrant and egregious;" (2) result from a pattern or practice on the part of the state or the facility involved; (3) result in "grievous harm to the patients or residents at the facility," and (4) deprive the institutionalized persons of identifiable constitutional rights.

I should further note that the Act requires the Department to attempt to resolve issues through conciliation and negotiation before it turns to litigation as a last resort. If successful, the rights of institutionalized persons receive the full measure of constitutional protection far more rapidly and comprehensively than could ever be accomplished through protracted litigation. Our enforcement efforts have, therefore, sought in each case to resolve our constitutional concerns through meaningful negotiations -- and have met with considerable success by utilizing that approach. Where, however, negotiations have broken down, or come to an impasse, we have not hesitated to turn to the courts for needed relief. This approach is the one mandated by Congress and the one that has proved most effective in carrying out our CRIPA enforcement responsibilities. A constant reevaluation of our activities in this area convince us that there is no sound reason to depart from the course we are on.

The Department is fully committed to the protection of the rights of mentally ill and mentally retarded persons. We continue to believe that the protection of the rights of those less fortunate individuals who must be confined in institutions deserve our utmost attention and our determined action. We are sensitive to their needs, concerned about their welfare, and dedicated to their protection.

Our record under CRIPA demonstrates the strength of our resolve. Since the statute's enactment in 1980, the Department has begun investigations of 15 mental hospitals and 11 mental retardation facilities. All but two of these investigations have been initiated during the Reagan Administration. Of the 26 investigations, 14 are still open. Of the 12 that have been closed, four resulted in the filing of a complaint and accompanying consent decree in court. The remaining eight have produced substantial voluntary remedial efforts aimed at redressing the constitutional deficiencies we had identified. This is hardly a record that suggests a lack of "aggressiveness," or an insensitivity to the rights of mentally ill and mentally retarded persons.

It is also important to note that our enforcement activities under CRIPA are not limited to facilities for mentally ill and mentally retarded persons. We have been equally vigorous in the area of prisons, jails, and juvenile detention facilities. In these areas, we have initiated 27 investigations, 7 of which are still open. Two cases resulted in substantial court-ordered remedial measures (both by consent decree), and 12 investigations resulted in substantial voluntary remedial efforts that obviated the need to file suit.

The specific criticisms in the Report of the Department's activities under CRIPA are not well-documented. Unnamed "observers" (e.g., Report at 141) and the remarks of two former attorneys with the Civil Rights Division apparently formed the principal bases of the Subcommittee staff's allegations that the Department has not aggressively pursued the protection of the rights of those confined in state mental health facilities. These allegations -- many of which have been raised and answered before -- are utterly without foundation.

The Report states that, since the hearing at which I testified in November 1983, six investigations of state mental health and mental retardation facilities were initiated by the Department (Report at 152). In fact, there are seven. The Report was apparently prepared prior to the opening of our investigation of the Kalamazoo Regional Psychiatric Hospital in Michigan. Pursuant to CRIPA, notice of that investigation was provided to appropriate State officials in February 1985.

Our attorneys have met with officials of each of the six states in which the named facilities are located and have visited each of them along with experts retained by the Department to assist in our investigations. The two investigations begun in the last two months of 1983 in Michigan and Colorado are complete, state officials have been notified of our findings, and we are completing negotiations with the states to secure judicially enforceable settlement agreements. The Michigan State legislature has, as a resulr of our investigation of Northville and Ypsilanti Regional Psychiatric Centers, appropriated $14 million for improvements at the Northville facility alone. The State has hired 34 additional nurses at the Ypsilanti facility and already has reduced the patient population, with further reductions planned. We consider these results significant vindication of our approach to conciliate rather than resort to premature and potentially lengthy litigation to achieve needed improvements.

With respect to the four other investigations on page 152, which the Report correctly indicates were begun in 1984:

(1) The South Beach Psychiatric Center investigation was closed in November 1984 after tours in April and August 1984 by our attorneys and consultants revealed that the conditions that prompted our investigation had been voluntarily remedied by the Center. South Beach is presently certified by both the JCAH and HHS.

(2) The investigation at Southbury Training School in Connecticut has been completed. Our attorneys and consultants visited the School on three occasions. We anticipate that our Notice of Findings letter will be forthcoming in the near future.

(3) Our investigation of Belle Chasse State School in Lousiana is moving rapidly. It began on November 30, 1984, with the sending of the required notification letter. In January 1985, our attorneys met with state officials to discuss issues and procedures for the investigation. Our attorneys have already spent two days reviewing

records and toured the facility with two expert consultants on March 6-7, 1985.

(4) The investigation of the Fort Stanton Hospital and Training School in New Mexico, which began in December 1984, is also proceeding. We have already completed one tour of the Fort Stanton School with two of our experts. Whether further investigation is warranted will depend, of course, on the reports of these consultants and our evaluation of them.

Finally, in the investigation of the Kalamazoo Regional Psychiatric Hospital, which was initiated in February 1985 and is not referenced in the Report, our attorneys have begun collecting information. In mid-March 1985, Department attorneys met with Hospital officials. Shortly thereafter, Department attorneys conducted a two-day tour of the Hospital with two expert consultants in the mental health field.

Thus, during the past 17 months since the last Senate hearing, the Department has actively pursued its investigations of these seven facilities.

During that same 17-month period, we have achieved significant results in our other investigations. In March 1984, we obtained a judicially enforceable consent decree with the State of Indiana with respect to Central State Hospital and Logansport State Hospital. The state not only committed to meet constitutional standards at the two facilities under investigation, but also volunteered to evaluate its three other mental hospitals and agreed to follow the requirements of the Consent Decree in those facilities as well. As a result of our investigation and negotiation, Indiana also committed to hire 550 additional employees (a 13.5 percent increase in staff). The Indiana Mental Health Department has indicated that it may seek as much as $30 million from the legislature for capital improvements in its psychiatric hospitals.

In January 1985, we obtained a judicially enforceable consent decree requiring the State of Maryland to provide constitutional conditions of confinement at Rosewood Center. The State has already submitted plans for correcting the unconstitutional conditions that were found to exist at that facility, and the Governor has sought an additional $7.3 million in funds for Rosewood.

South Carolina, as well, has responded to our efforts at negotiation. On March 28, 1985, Governor Riley informed me of steps the State had taken or intends to take with respect to the South Carolina State Hospital, including seeking $4.5 million in additional funds, reducing patient population at the Hospital to 700 from 1100 patients, and providing additional staff training and more qualified staff. As well, South Carolina expects to open a new facility, the Harris Psychiatric Hospital, in June 1985. We have not yet determined whether the Remedial Action Plan of the State remedies all of our concerns regarding unconstitutional conditions at the Hospital.

Of the remaining investigations referred to on pages 143-144 of the Report, several have been closed due to voluntary compliance, a few have been closed because the conditions at the facilities did not warrant further proceedings under CRIPA, and several are at various stages of negotiation (with the possibility of consent decrees being entered in three different jurisdictions in the near future).

Thus, we have, in fact, made significant progress in virtually all of our investigations without having to resort to litigation. But, as I testified last year before Committees in both Houses, when the occasion arises where the conciliation process mandated by CRIPA does not resolve or remedy unconstitutional conditions found to exist at a facility, the Department will not hesitate to pursue the matter in court. In February 1985, the Department filed a suit under CRIPA against the State of Massachusetts. Our endeavor to remedy the unconstitutional conditions of confinement at Worcester State Hospital were met with unyielding resistance. We therefore resorted to legal action. This is the third lawsuit filed by the Department under CRIPA following the failure of negotiations. [The first involved a State correctional facility and the second involved a city jail.]

In sum, the Department has a solid record of action under CRIPA. Our motivating force is the protection of the constitutional rights of persons confined in state institutions. Our guiding principles are adherence to the role prescribed for us by Congress in the statute and fidelity to the rulings of the Supreme Court as to the constitutional protections that are due institutionalized persons. We continue to believe that our role under CRIPA, although carefully circumscribed by the legislation, is an exceedingly important one. The experience of the past four years underscored the soundness of Congress' approach to federal involvement in this area. By using the tools of persuasion and negotiation in the first instance, and resort to litigation only if an agreed solution cannot be found, the Department has effectively used CRIPA to protect the constitutional rights of more people at more institutions over less time than we ever could have achieved through a reflex rush to the courthouse to commence protracted lawsuits.

We are proud of our enforcement record under CRIPA, as well we should be. But our satisfaction with the past results will not lull us into being any less active in the months and years ahead. The statute provides the largest measure of protection against constitutional deprivations suffered by those confined to institutions, and we intend to ensure that every safeguard available under CRIPA is and continues to be fully realized by the statute's intended beneficiaries.

Senator **Weicker**. Our first panel today consists of Elizabeth Merilatt of Albuquerque, NM; Helen Lopez of New Mexico State Hospital; and Charles Zdravesky—am I supposed to pronounce the "Z"?

Mr. **Zdravesky**. No; the "Z" is silent.

Senator **Weicker**. Zdravesky is correct?

Mr. **Zdravesky**. Yes; it is.

Senator **Weicker**. And Charles Zdravesky of Albuquerque, NM. So why don't we proceed with our first panel in that order, and I believe Elizabeth Merilatt of Albuquerque is our first witness.

STATEMENTS OF ELIZABETH MERILATT, ALBUQUERQUE, NM; HELEN LOPEZ, R.N., NEW MEXICO STATE HOSPITAL, LAS VEGAS, NM; AND CHARLES ZDRAVESKY, ALBUQUERQUE, NM

Ms. **Merilatt**. Thank you. Shall I go ahead?

Senator **Weicker**. Go right ahead. Just pull that microphone right up and speak right out—you are among friends, and we very much want to hear what you have to say.

Ms. **Merilatt**. If I speak too fast, please let me know.

Senator **Weicker**. I will.

Ms. **Merilatt**. I timed it about 20 minutes, and I don't want to run too much over that.

Senator **Weicker**. I think what I would like to do, because we do have three panels today, is to sort of keep the testimony to around 10 minutes or so because there will be questions that I will want to ask.

Ms. **Merilatt**. Yes.

Senator **Weicker**. You go right ahead, and make sure that we get your story—that's what I want, that's the main thing.

Ms. **Merilatt**. The mentally ill are among the most misunderstood, sensitive, and fragile of our citizens. Certainly they, of all God's creatures, deserve compassionate and tender care. It has been proven that even the most seriously disturbed respond and improve under good care. Yet late in the 20th century, in our country of high technological advance, there is shameful mistreatment of the mentally ill. Our son is one of those who has received unwarranted abuse and neglect in a State mental hospital.

Let me tell you of what occurred at the New Mexico State Hospital at Las Vegas from January until September 1983. First, a few bits of background information about Scott: He was 24 when he was sent to Las Vegas, sent there because the court said he was a chronic schizophrenic who could not be treated any longer at the county mental health center in Albuquerque. They said that Las Vegas was equipped to treat long-term mental patients and BCMHC was not. Schizophrenia in two-thirds of the cases is a long-term illness, so there you have it: under our system most of this type mental patient are foredoomed to end up at the State mental hospital, usually far from the supporting influence of family and friends.

Our son's illness began when he was 19, in his first year of college. He was able to complete only one semester after that, and has not been able to hold a permanent job.

In the years since then he has been in and out of hospitals intermittently every 3 to 6 months. He has serious side effects from long-term medicating. Yet in spite of this shattering illness, Scott is a bright young man with math and art skills well above average. These traits were detailed in a letter we wrote to the admissions office at Las Vegas when Scott was sent there, so facts of his history, talents, and personality could be used to his benefit in drawing up a treatment plan for him. Yet in the 206 pages of Scott's records received recently, in response to our request, there are exactly five mostly blank pages of a "behavioral intervention plan" for our son. The last page states that the plan was deferred. Remarks were never entered upon it again in the nearly 9 months Scott spent at Las Vegas.

Treatment recommendations, part of the two pages of admission notes, were also deferred. The doctor's admission notes did say, though, that Scott had "overprotective parents." Our letter with notes on his history might have provoked this conclusion. Or the fact that we made a visit there 2 months earlier to find out what Las Vegas was really like. That visit gave us no hint of what life at Las Vegas would be like for Scott, however. We were shown only the new, open cottage area where patients are kept for 2 weeks after arrival. The dismal, bleak back wards where long-term patients live were not shown. We did visit him there, though, and each time came away with a hopeless feeling of despair and anger.

If Scott was treated like this at Las Vegas, with parents who visited monthly and complained to officials after each visit, and his twin brother who visited almost weekly toward the end of his stay and was extremely vocal in criticism, what of others who had no advocates? We can only speculate what their records, if kept in any candor, would reveal.

To the point of this testimony: In nearly 9 months at the State Hospital, his records show, Scott was attacked by other patients without provocation on nine separate occasions. On four other occasions, serious injuries were reported. These are physical attacks. Mental harassments have not been reported. On April 24, Mike G. hit him with his fist while Scott was sitting in the dayroom; red area, neck and cheekbone. On April 27, Dennis O. hit him on the right eye; swelling and discoloration. On June 9, while walking in the dayroom, Mike G. again hit and kicked Scott; abrasion, lower right back. On July 23, Scott was taking a bath; a patient, Eli H. struck him in the back; red area on back. On July 24, Scott walking down the hall, a patient hit him; abrasions, both cheekbones, old cut opened on right elbow, red area on shoulder. On July 25, while walking down the hall, Eli H. again attacked, this time kicking him. On August 1, Scott punched by L.B.; redness and swelling over left eye. On August 9, punched again by L.B.; redness in the cheekbone area. On August 27, Scott in the bathroom when patient Bill F. struck him in the back; large red area.

Other injuries noted: On April 15, Scott reported he had been "beat up." On June 18, Scott was noticed to have a black eye. On June 18, later in day, staff said he "made himself fall." We happened to call when he was in infirmary for stitching of lacerations. On June 20, ear was bleeding, blood coming out of the ear. This time an x ray of his skull was taken, showing no concussion. I thought possibly he had fainted from malnutrition, but his sister later told us Scott said he had tried to fall, to do away with himself, since life had become unbearable.

Indeed it had. He said later that "It was like hell. It was 100 times worse than BCMHC." The records show that in 9 months at Las Vegas Scott tried to escape 30 times. He succeeded six of them, sometimes into bitterly cold weather, in mountainous country, scantily clad. For this he was put into seclusion for 8 hours, a total of 19 times. Into restraints for 8 hours another nine times. Do you know what posey restraints or five-point restraints are? They are the body points where the patient is tied to a chair to restrain him. We hear of hostages being treated in this manner. This is by persons who consider themselves our enemies.

Another form of abuse, I feel, is taking away a person's sense of his own dignity. Even hardened penitentiary inmates feel they are entitled to be treated with respect and to retain their dignity. So how must mental patients feel, sharing with as many as 20 others their dormitory quarters? They have no privacy to get dressed or undressed, to sleep, or share a personal telephone call with a loved one. All Scott's mail was opened and a note put in his file as to whether it contained money or not. They have no decent place to keep their few personal possessions.

Of course, while Scott was at Las Vegas, all his clothing, every one of his personal possessions, vanished. The only thing sent back was the suitcase his clothes and toilet items were packed in for his trip up there. The person who checked in his items said there had been no money—and in fact there had—in his suitcase. The Easter gift that we took him, a beautiful pair of soft leather shoes, which he expressed great delight in, disappeared by our next visit, and no one knew anything about it. He was wearing an ugly pair of hand-me-downs from hospital issue.

As well as the affront on personal dignity, the State hospital offers its patients no opportunities for pursuits which the intellect as well as the soul starves without. Where are the good books, classical and church music, art expressions that afford a mental patient—indeed, all of us—relexation, growth, and a sense of joy of life? Is there only the blaring television set high on the dayroom wall, too stark and loud for patients such as our son who has difficulty sorting out sensory details at best. Or the snakepit scene that I shall never forget of our second visit: women and men, young and old, marching up and down, singing loudly and repetitively, people with all manner of mental problems, no attempt made to segregate them as to type.

So much for abuse, physical as well as mental. As for neglect, during the 9 months of Scott's stay at Las Vegas, he was seen by the doctor assigned for his care and treatment only eight times—not even once a month. Comments in Scott's chart by doctors are very brief. No treatment plan—that is why they wouldn't send us his—or progress reports in the file; a very slight attempt shown to associate behavior with medication; a long-term treatment reference almost entirely missing. His parents were called only two times, both to report he was missing—never for progress reporting. All telephone calls were made by us. Scott himself had almost no access to phones; he had been in the habit of calling regularly and we had assured staff we would accept collect phone calls; he called us only twice in 9 months' time. Once, a most delightful call, he had gone on a picnic and picked wild flowers. His description of their vivid colors was almost ecstatic.

Other aspects of neglect: The counselor assigned to Scott had 17 or 18 patients to oversee. If he spent all his working time with patients, that meant that each one would get 2 hours and 18 minutes of his time each week. Beyond this and the doctor's once-a-month cursory visit, no treatment. Of the 206 pages of Scott's file, about 150 were termed "Progress Notes," an ironic title. Day after dreary day, they recorded remarks of clearly uneducated and insensitive ward attendants: "Patient was well-groomed" or "was confused by cooperative." Or "patient this shift extremely lazy and showing no initiative." Or "patient has been well complying."

Neglect by qualified personnel? Yes. But more than that. A grim philosophy, put forward by we knew not who, of stubborn insistence upon conformity to a so-called treatment program that never was put into writing or explained in our one consultation visit at Las Vegas. Expressed in these words over the telephone by the overworked counselor to me: "We may have to break Scott's spirit to get him to conform to our program and treatment schedule." My husband wrote a letter in response to that remark. It was never answered, as was the case with all our written communications. There was simply no accountability there.

When we realized this, after the June conference with the doctor, which had been interminably postponed, I wrote the clinical director of the hospital. He assured me over the telephone that as taxpayers we did not have to put up with the miseries we were experiencing. At that time, not knowing of the physical abuse, it was the fact that Scott was steadily and frightfully deteriorating day by day. Nothing was ever put in writing by this man, only the dishonest verbal assurances came from his telephone calls.

From the time the plan was formed in the court hearing in Albuquerque to send Scott to Las Vegas, vigorously opposed by us, but powerless to prevent, we feared for him. Yet not in our wildest dreams, and we have had many, did the fears come close to the reality. At one point we actually feared for his life. We felt that because of his extreme emaciation, he would be prey to illness and we would lose him. My journal shows that on our very first visit to see him, 4 weeks after his arrival, he was in deplorable condition:

> Met Phil, went to see Scott and shocked at his condition. So gaunt and hollow, sunken-eyed, he is undeniably in the worst shape he has ever been in, thin as bones, shaking, et cetera. Could not even slice the lemon we brought or hold it to eat. We did not stay as long as planned because it was so heartbreaking and he could not even converse very well, even with Philip. After we got outside, Philip and I both broke down and cried. We thought that this must have been what the death camp victims were like.

And on the visit in June, which Scott could not partake in, when we finally got to see his doctor:

> Scott's weight loss was again frightening. He was emaciated and catatonic. George spent most of the visit holding him in his arms to give him some comfort. He did not speak to us at all.

The hospital nurses would promise to send us figures on his weight loss but never did. The chart figures, which I disbelieve, show that he weighed 135 pounds at admission, 125 in August. He had lost much more than that, I am sure.

You might well ask: And why did you allow this to go on? We were in a catch-22 situation. We were not informed when Scott had served his 6-month commitment at Las Vegas, and when we asked were told the commitment time had passed but that he was remaining on a voluntary basis. We received no papers, nothing in writing, when he was committed, so we had assumed he had to stay there 6 months from arrival date. Actually it was 6 months from the court order which set out terms for his being sent there.

When we realized he could leave, we then were faced with the ever-present problem of mental patients' parents: Where will he go now? The county mental health center would not take him because he was "long-term." In limbo with his insurance coverage, we could not check him into a private hospital until open season at year's end for changing insurance companies. [The State hospital was far behind in billing; when I checked in June, they had not billed at all. They said they would instead turn it over to their "legal" who would decide whether to bill us, since we were unhappy with Scott's care.] So somehow we had to get BCMHC, the county mental health center, to accept him again. We knew the director there, a kind and compassionate man. From June until September, we worked with him and he with Las Vegas, to get approval for Scott's return to Albuquerque. We had to be very careful, not push anyone too hard, for fear of the whole plan's falling through. Even after Scott returned to BCMHC, that director was under pressure to send Scott back to Las Vegas, during the 4 months we had to wait for new insurance coverage.

So Scott spent almost another 4 months in agony while we were desperately trying to find a place for him. We even got an appointment with our U.S. Representative, but this produced no results. We were in touch with the State attorney general's office about the absence of a treatment plan and response from the staff, but had to ask them to hold off until we knew for sure he could go back to Albuquerque.

Consider working with a situation such as this for your son. I quote again from my journal:

June 9: Called David the counselor and told him we were tired of waiting for Dr. Scharf to decide when we would have a conference, to include Scott, and he said he would set an appointment then for George and me with him for 2 p.m. Wednesday, June 15.

June 12: Called Scott and he is very bad, hardly speaking, no response to questions.

June 14: Revised the letter and sent to Dr. Scharf.

June 15: Visit with Dr. Scharf, David and Dr. John Rohrbach, first we knew he existed. All over hospital to find Dr. Scharf, no one knew where he was, took 40 minutes to locate him. Bad visit. Dr. Scharf suggested we not visit or call Scott so much—had been calling him once a week at his suggestion. Alarmed at Dr. Scharf's demeanor, and going to sleep several times during the visit, responding in monosyllables and letting David and Dr. Rohrbach answer most of our questions. He could give no explanation for Scott's frightening weight loss.

June 16: Called Dr. Keightley and told him how concerned we were over Scott and intended to take him out of Las Vegas hospital. Called David and he made the remark about "may have to break Scott's spirit."

No one knows how long it will take our son to regain all that was lost at Las Vegas, or whether he will ever be able to erase the marks it has put upon him. I doubt whether a normal person could have handled it as well as he did. But he is making progress. When we changed insurance policies, Scott went into a private hospital in Albuquerque where he spent almost the entire year 1984, wiping out his lifetime maximum insurance benefits with that company. But he improved enough to go into a private halfway house in mid-December. [Community-supported housing is almost nonexistent in New Mexico. A total of 35 rooms are available in Albuquerque for a schizophrenic population alone of 3,500.]

Scott is doing reasonably well there. We hope the improvement will continue. He is reading and working with math again, socializing, painting at his easel, going for walks and seeming to enjoy a measure of contentment.

[The prepared statement of Ms. Merilatt follows:]

TESTIMONY OF ELIZABETH MERILATT

(PARENT)

ALBUQUERQUE, NEW MEXICO

The mentally ill are among the most misunderstood, sensitive and fragile of our citizens. Certainly they, of all God's creatures, deserve compassionate and tender care. It has been proven that even the most seriously disturbed respond and improve under good care. Yet late in the 20th century, in our country of high technological advance, there is shameful mistreatment of the mentally ill. Our son is one of those who has received unwarranted abuse and neglect in a state mental hospital.

Let me tell you of what occurred to him at the New Mexico State Hospital at Las Vegas from January until September of 1983. First, a few bits of background information about Scott: he was 24 when he was sent to Las Vegas, sent there because the court said he was a chronic schizophrenic who could not be treated any longer at the County Mental Health Center in Albuquerque. They said that Las Vegas was equipped to treat long-term mental patients and BCMHC was not. Schizophrenia in two-thirds of the cases is a long-term illness, so there you have it: under our system most of this type mental patient are foredoomed to end up at the State Mental Hospital, usually far from the supporting influence of family and friends.

Scott is a bright young man, with math and art skills well above average. These traits were detailed in a letter we wrote to the admissions office at Las Vegas when Scott was sent there, so facts of his history, talents and personality could be used to his benefit in drawing up a treatment plan for him. Yet in the 206 pages of Scott's records received recently in response to our request, there are exactly five mostly blank pages of a "behavioral intervention plan" for our son. The last page states that the plan was deferred. Remarks were never entered upon it again, in the nearly nine months Scott spent at Las Vegas.

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To the point of this testimony: in nearly nine months at the State Hospital, Scott was attacked by other patients, without provocation, on nine separate occasions. On four other occasions, serious injuries were reported. These are physical attacks: mental harassments have not been reported. On April 24, Mike G. hit him with his fist while Scott was sitting in the dayroom. Red area, neck & cheekbone. On April 27, Dennis O. hit him on the right eye; swelling & discoloration. On June 9, while walking in the dayroom, Mike G. again hit and kicked Scott; abrasion lower right back. On July 23, Scott was taking a bath; a patient, Jerry H., struck him in the back; red area on back. On July 24, Scott walking down the hall; a patient hit him; abrasions both cheekbones, old cut opened on right elbow, red area on shoulder. On July 25, while walking down the hall, Jerry H. again attacked, this time kicking him. On August 1, Scott punched by J.B.; redness and swelling over left eye. On August 9, punched again by J.B.; redness in cheekbone area. On August 27, Scott in bathroom when patient Ken F. struck him in back; large red area.

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Indeed it had. He said later that "It was like hell. It was 100 times worse than BCMHC." The records show that in nine months at Las Vegas Scott tried to escape 30 times. He succeeded six of them, sometimes into bitterly cold weather, in mountainous country, scantily clad. For this he was put into seclusion for eight hours a total of 19 times. Into restraints for eight hours another nine times. Do you know what posey restraints or 5-point restraints are? They are the body points where the patient is tied to a chair to restrain him. We hear of hostages being treated in this manner. This is by persons who consider themselves our enemies.

Another form of abuse, I feel, is taking away a person's sense of his own dignity. Even hardened penitentiary inmates feel they are entitled to be treated with respect and to retain their dignity. So how must mental patients feel, sharing with as many as 20 others their dormitory quarters? They have no privacy to get dressed or undressed, to sleep, or share a personal telephone call with a loved one. They have no place to keep their few personal possessions. Of course, while Scott was at Las Vegas, all his clothing, every one of his personal possessions vanished anyway. The only thing sent back was the suitcase his clothes and toilet items were packed in for his trip up there. The person who checked in his items said there had been no money (and in fact there had) in his suitcase. The Easter gift that we took him, a beautiful new pair of soft leather shoes, which he expressed great delight in, had disappeared by our next visit and no one knew anything about it; he was wearing an ugly pair of hand-me-downs from hospital issue.

As well as the affront on personal dignity, the State Hospital offers its patients no opportunities for pursuits which the intellect as well as the soul starves without. Where are the good books, classical and church music, art expressions that afford a mental patient, indeed all of us, relaxation, growth and a sense of joy of life? Is there only the blaring television set high on the dayroom wall, too stark and loud for patients such as our son who have difficulty sorting out sensory details at best. Or the snake-pit scene that I shall never forget, of our second visit....women and men, young and old, marching up and down, singing loudly and repetitively, people with all manner of mental problems, no attempt made to segregate them as to type.

So much for abuse, physical as well as mental. As for neglect, during the nine months of Scott's stay at Las Vegas, he was seen by the doctor assigned for his care and treatment only 8 times. Not even once a month. Comments in Scott's chart by doctors are very brief. No treatment plan (that is why they wouldn't send us his) or progress reports in the file. A very slight attempt shown to associate behavor with medication. A long-term treatment reference almost entirely missing. His parents were called only two times, both to report he was missing. Never for progress reporting. All telephone calls were made by us. Scott himself had almos no access to phones; he had been in the habit of calling regularly and we had assured staff we would accept collect phone calls; he called us only twice in nine months' time. Once, a most delightful call, he had gone on a picnic and picked wild flowers. His description of their vivid colors was almost ecstatic.

Other aspects of neglect: the counselor assigned to Scott had 17 or 18 patients to oversee. If he spent all his working time with patients, that meant each one would get two hours 18 minutes of his time each week. Beyond this and the doctor's once a month cursory visit, no treatment. Of the 206 pages of Scott's file, about 150 were termed "Progress Notes", an ironic title. Day after dreary day, they recorded remarks of clearly uneducated and insensitive ward attendants: "Patent was well-groomed" or "was confused but cooperative". Or "patient this shift extremely lazy and showing no initiative". Or "patient has been well complying".

Neglect by qualified personnel? Yes. But more than that. A grim philosophy, put forward by we knew not who, of stubborn insistence upon conformity to a so-called "treatment program" that was never put into writing or explained in our one consultation visit at Las Vegas. Expressed in these words over the telephone by the overworked counselor to me: "We may have to break Scott's spirit to get him to conform to our program and treatment schedule." My husband wrote a letter in response to that remark. It was never answered, as was the case with all our written communications. There was simply NO ACCOUNTABILITY there.

When we realized this, after the June conference with the doctor, which had been interminably postponed, I wrote the clinical director of the hospital. He assured me, over the telephone, that as taxpayers we did not have to put up with the miseries we were experiencing. At that time, not knowing of the physical abuse, it was the fact that Scott was steadily and frightfully deteriorating day by day. Nothing was ever put in writing by this man, only the dishonest verbal assurances came from his telephone calls.

From the time the plan was formed in the court hearing in Albuquerque to send Scott to Las Vegas, vigorously opposed by us but powerless to prevent, we feared for him. Yet not in our wildest dreams, and we have had many, did the fears come close to the reality. At one point we actually feared for his life. We felt that because of his extreme emaciation, he would be prey to illness and we would lose him. My journal shows that on our very first visit to see him, four weeks after his arrival, he was in deplorable condition: "Met Phil, went to see Scott and shocked at his condition. So gaunt and hollow, sunken-eyed, he is undeniably in the worst shape he has ever been in, thin as bones, shaking, etc. Could not even slice the lemon we brought or hold it to eat. We did not stay as long as planned because it was so heartbreaking and he could not even converse very well, even with Philip. After we got outside, Philip and I both broke down and cried. We thought that this must have been what the death camp victims were like."

And on the visit in June, which Scott could not partake in, when we finally got to see his doctor: "Scott's weight loss was again frightening. He was emaciated and catatonic. George spent most of the visit holding him in his arms to give him some comfort. He did not speak to us at all."

The hospital nurses would promise to send us figures on his weight loss but never did. The chart figures, which I disbelieve, show that he weighed 135 pounds at admission, 125 in August. He had lost much more than that, I am sure.

You might well ask: And why did you allow this to go on? We were in a Catch 22 situation. We were not informed when Scott had served his six-month commitment at Las Vegas, and when we asked, were told the commitment time had passed but that he was remaining on a voluntary basis. We received no papers, nothing in writing, when he was committed, so we had assumed he had to stay there six months from arrival date. Actually, it was six months from the court order which set out terms for his being sent there.

When we realized he could leave, we then were faced with the ever-present problem of mental patients' parents: where will he go now? The County Mental Health Center would not take him because he was "long-term". In limbo with his insurance coverage, we could not check him into a private hospital until open season at year's end for changing insurance companies (The State Hospital was far behind in billing; when I checked in June, they had not billed at all. They said they would instead turn it over to their "legal" who would decide whether to bill us, since we were unhappy with Scott's care.)

So, somehow, we had to get BCMHC (the county mental health center) to accept him again. We knew the director there, a kind and compassionate man. From June until September, we worked with him and he with Las Vegas, to get approval for Scott's return to Albuquerque. We had to be very careful, not push anyone too hard, for fear of the whole plan's falling through. Even after Scott returned to BCMHC, that director was under pressure to send Scott back to Las Vegas, during the four months we had to wait for new insurance coverage.

So Scott spent almost another four months in agony while we were desperately trying to find a place for him. We even got an appointment with our U.S. Representative but this produced no results. We were in touch with the State Attorney General's office about the absence of a treatment plan and response from the staff, but had to ask them to hold off until we knew for sure he could go back to Albuquerque.

Consider working with a situation such as this for your son: I quote again from my journal: June 9: Called David the counselor and told him we were tired of waiting for Dr. Scharf to decide when we would have a conference (to include Scott) and he said he would set an appointment then for George and me with him for 2 pm Wednesday June 15.

June 12: Called Scott and he is very bad, hardly speaking, no response to questions.

June 14: Revised the letter and sent to Dr. Scharf.

June 15: Visit with Dr. Scharf, David and Dr. John Rohrbach (first we knew he existed). All over hospital to find Dr. Scharf, no one knew where he was - took 40 minutes to locate him. Bad visit. Dr. Scharf suggested we not visit or call Scott so much (had been calling him once a week at his suggestion). Alarmed at Dr. Scharf's demeanor, and going to sleep several times during the visit, responding in monosyllables and letting David and Dr. Rohrbach answer most ~~for~~ our questions. He could give no explanation for Scott's frightening weight loss.

June 16: Called Dr. Knightley and told him how concerned we were over Scott and intended to take him out of Las Vegas Hospital. Called David and he made the remark about "may have to break Scott's spirit".

No one knows how long it will take our son to regain all that was lost at Las Vegas, or whether he will ever be able to erase the marks it has put upon him. I doubt whether a normal person could have handled it as well as he did. But he is making progress. When we changed insurance policies, Scott went into a private hospital in Albuquerque where he spent almost the entire year 1984 (wiping out his lifetime maximum insurance benefits with that company). But he improved enough to go into a private halfway house in mid-December. (Community supported housing is almost non-existent in New Mexico. A total of 35 rooms are available in Albuquerque for a schizophrenic population alone of 3,500.)

Scott is doing reasonably well there. We hope the improvement will continue. He is reading and working with math again, socializing, painting at his easel, going for walks and seeming to enjoy a measure of contentment.

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Senator Weicker. Mrs. Merilatt, your son was at New Mexico State Hospital for 9 months with no active plan of treatment, yet I understand New Mexico law requires that a treatment plan be developed within 14 days; is that correct?

Ms. Merilatt. Yes; that is correct. I have a quote from a recent book on the legal aspects of mental health that states that—it says this New Mexico law, 43-1-6 of the statute states:

> The client has a right to prompt treatment. An individualized treatment or habilitation plan shall be prepared within 14 days of a client's admission.

Do you want me to read the details of that?

Senator Weicker. No; I was just wondering whether you might give an explanation as to why Scott received no treatment plan.

Ms. Merilatt. That was hard to understand. I finally concluded that they didn't want to put anything in writing to reveal that they did not have a treatment plan. Assurances were given of taking his weight and all that, but that was never done or never given. Nothing was ever put in writing, and we didn't discover that they, in fact, had no treatment plan until we sent for his records, and we got those only after almost a year.

Senator Weicker. In your testimony you cite numerous instances of assault against your son. How were you informed by hospital officials of these incidents?

Ms. Merilatt. They never informed us, Senator Weicker. We got that information also from the records. Everything that I have put in here, there were other types of assault that I haven't put in, because I don't have the documentation for it. It was never in the record; we were never informed of any of these beatings of our son. The time that he did make himself fall and had the laceration, we happened to call at the time that he was having the stitches.

Senator Weicker. Couldn't you see the results of these beatings when you went to visit Scott?

Ms. Merilatt. It so happened that that was timed at a place—they were mostly in June—that was timed at a place where we wondered about it, but we weren't really sure; most of it was under his clothing. But we did worry and we saw completely the results of his emaciation and terrible loss of weight. And he did get two infections while he was there as well. We noticed those and asked about them.

And there were two nurses that were, I thought, very caring and would always try to take care of the infections, for example. But they were one of the ones that promised us the weight—they started giving him this Insure, which is a protein drink, but that was about the only thing as far as response to our complaints, as far as that, that was done.

Senator Weicker. All right, I might have further questions, but let me proceed with the rest of our witnesses.

The next witness that we have is Helen Lopez, who was a nurse at the New Mexico State Hospital. Ms. Lopez was subpoenaed here today, so I would appreciate it if she would stand and take the oath.

[Ms. Lopez was duly sworn.]

Senator Weicker. Why don't you proceed with your testimony, as you deem fit.

Ms. Lopez. I started working at the New Mexico State Hospital in April of 1977. After a month I was appointed supervisor of the acute medical and surgical unit and advised to get the unit ready for certification. One of the officials from the main office in Santa Fe was very upset with the director of nurses because she had not done anything at all to improve conditions during the several years she had been director of nursing.

Besides performing the daily duties as supervisor, I had to do all the paperwork that was required: nursing care plans for every patient we admitted and procedures for carrying them out; update the policy and procedure manual; outline the inservice to be given for the staff and make out the lesson plans for this inservice; make job descriptions for RN's, LPN's, and attendants working in the unit. I was offered no help so I had to do most of the paperwork at home.

Medical service passed inspection after 1 month of preparation. I had problems, because the RN's, LPN's, and attendants wanted to do procedures their way, not according to the nursing manual. Because I was trying to initiate the following of proper procedure and because of their refusal to do it, I started finding myself before the union on a weekly basis. Valuable time I could have used to do something for the patients I had to spend trying to defend myself from administrators, director of nursing, union leader, and attendants. That was to be my way of life there. In this unit I saw an unexplained fracture and a dislocated shoulder caused by improper handling, both very painful to the patient.

After the above unit was certified, the administrators decided they could make more money if they opened another unit, which was Ponderosa 1, and turned it into a skilled nursing unit. They wanted the money, but little did they think of the requirements to keep the unit certified. The care of those patients already in this unit should have been getting skilled nursing care even if it was not a requirement. They were not being turned, they were not gotten out of bed, they were getting even less than assembly line care. None of the nurses wanted to be supervisor of this unit. I volunteered because, knowing the attitude of some of the nurses, I did not want them to say "I did not ask for this" and the patients would have to pay for it.

Again, I did not get any kind of help from anyone. Instead, between the administrators, director of nurses, nurses, and attendants, I was being undermined in my efforts. When I asked the attendants to do something, the nurses told them not to do it and encouraged the attendants only to report me to the union, which they immediately did.

In spite of all the resistance from the staff and no help from the administrators, I got the unit certified with deficiencies that should never have happened, such as attendants refusing to use bath blankets to cover patients while bathing them, closing the doors while bathing and dressing them, not getting them out of bed when assigned to do so. One of the hardships was the refusal of the administrators to give me the help I needed. I had myself and another RN for days, and one LPN, to work each shift. They kept telling me I had nothing to do in that unit, there was nothing to do there. We were so short of attendants, I had to assign myself some patients for baths when someone was missing. They had eight or nine patients each for baths and care every day. The administrator said those patients did not need a bath every day. For 3 months I had to work double shifts and I could afford a few days off. Once I had to work 24 hours straight because there was no one to relieve me.

Of the help I had, attendants and LPN's missed work often. The administrator brought to work one attendant with a heavy, heavy hangover one day—he was a nonalcoholic. I kept wanting to get him fired or transferred because he performed so poorly. This was not done until he beat up one of the patients badly while he was bathing him at 10 o'clock in the morning. Another attendant we reported many times was drinking on duty. We found his bottles everywhere. He was eventually transferred to another unit where he was fired for patient abuse. But no one would tell me what he had done. Another attendant I wanted fired because I never knew what he was going to do next scalded a patient from the waist down and then proceeded to start peeling off the skin from the blisters that formed. Another LPN was in the same room while he was doing this and never noticed him. If I had not been making rounds, no one would have seen him. I was forbidden to supervise attendants by now, yet there was no one else to do it. One attendant washed a patient's bottom and her face in a very rough manner in front of the patient's daughter. The daughter became very upset and wrote to the administrator to complain, but nothing was done about it. The aide only kept on doing as she wished. One attendant left a very contracted patient in the whirlpool unattended. I missed the patient, couldn't find him, so I looked in the bathroom and there he was almost ready to drown, slipping into the water. I waited and the attendant did not return for 15 minutes. In this unit the attendants were generally very rough to the patients—they had them sitting up for 6, 7, and 8 hours without changing them, were hardly ever turned if not gotten up, poorly fed, poorly hydrated. I could not do much to change this.

I had already sent a list of patient abuses, and I will answer that, if you ask me later.

There was no oral care at all. The patients were always bruised, and we had several patients with dislocated shoulders because the attendants refused to use turn sheets for turning. Many of them had arthritis and they hurt when turned. They got no medication for it. Only one man that I know of received medication for his arthritis, and that was because he was alert and he was a relative of one of the administrators.

I kept telling the administrators that the reason attendants hated to do their work was because they were not made for this kind of work. The attendants would tell me they hated the patients, the only reason they were here was because they could not find any other kind of work. The administrators and nurses had been there so long they did not know any other kind of care that should be given the patients. They did not for 1 minute consider any aspect of the patients' feelings, comfort, or physical pain. Low moral was caused because only a chosen few were ever recognized for achievement, whether they deserved it or not, or for just doing what they were supposed to do.

I was transferred to the Zias—I was considered a poor supervisor, so I was transferred to the Zias, a unit for the mentally retarded, also a ward where they sent staff for punishment. I was told they were having trouble with missing narcotics; the patients were losing weight and the ward smelled very bad. The conditions I found were deplorable. It was filthy and smelled worse than a barn. The patients were not even getting custodial care. They had more than enough staff but the staff would stick together in one place and the patients wandered around the ward at their own will. If a patient got hurt, no one knew how. One patient woke up with a fractured leg one morning, one badly beaten. I called the director, who did not come; I called the director of nurses who came after the security man had come and taken pictures. The director of nurses came and tore up the pictures and the incident report that I had already written and the notes that I had entered in the patient's chart. Because they would not allow me to do anything about improving the conditions, I reported all of this to the medical doctor in charge of mental health in Santa Fe. Because of this I was put under the supervision of LPN's. Eventually I was transferred again to get me out of the way. Nothing was done to improve patient care.

The rest goes on to the alcoholism treatment unit, which I will skip. I will read when I was put on the medication team.

The LPN that I was put under was an LPN that could never pass her State boards. This nurse took care of a patient with a rectal temperature of 100, which would be 99 if taken orally. She charted she had given the patient a cold sponge and had opened the windows on one of the coldest nights of winter—this was for a temperature of 99 orally.

Nurses had the habit of giving the patients aspirin any time they asked for it. One time we had a patient who was allergic to aspirin. I taped a warning on a tape on the medication door so no one would give him aspirin. The above nurse did not like the idea, so she took this tape off the door. That very night the patient received aspirin and landed in the hospital with an allergic reaction

The attendants on this unit were allowing the patients to drink and just because I was reporting this, they threatened to beat me up, and put sugar in my gas tank and broke my windshield. All this to get rid of me, because the director of nurses had assigned me to the medication team, an idea of hers that violated all the R's in the rules for giving medication. This team was to give medication hospital-wide; this consisted of only four nurses. It was obvious they were not going to give medications on time. We did not know the patients on the ward, and the staff was very uncooperative in giving us any kind of information on the patients. We could not observe the effect of the medication on the patient; we did not take the orders off the chart. We were doing everything in the dark.

Once I was supposed to give phenobarbital to a patient I could not even arouse. I did not give it and advised the staff to check on her and advise me what the doctor wanted to do about this patient. I could not get a hold of the doctor myself, but had to go on. The next day the director of the unit got after me for not giving it, even though they were still having trouble arousing her. Another patient on this same unit came to me and asked for her lomotil. I saw that it had been given to her every time the team came by. I asked her if she had diarrhea, and she said yes. I asked the staff, and no one knew, so I asked them to observe her closely and, if she did have diarrhea, they should notify the doctor, because after all the medication she should not have any and the doctor should look into it. Apparently nothing was done. The patient was transferred later to another hospital where they found she was full of intestinal cancer. She got lomotil all the time she was there, and she died shortly after she was transferred from our hospital.

The narcotics were being kept in rooms where attendants had a key to. Patients were not getting their medication if they were not in the unit when the team came by. I advised the director of nurses of all the irregularities several times, and nothing was done. I finally told her I was going to report this to someone who might do something about it.

Again, the director of nurses found it easier to transfer me than to correct all the irregularities I had pointed out to her. She assigned me to the skilled nursing unit again—this is where I had been before and had been transferred out. Now they had three times as many nurses and twice as many attendants as when I was there, but the patients were not getting any better care. They told me they had moved me because they were so short of help. They had hired a nurse that was supposed to be an authority on PSRO and certification needs. She did not know anything and didn't do anything. She was hired as a nurse V at a very high salary. Her way of handling problems was: "I don't want to hear about it." That was supposed to end the problem. The reason they considered themselves short was because this nurse had allowed the supervisor of the unit to go on 2 weeks of sick leave. The supervisor was really in Florida looking for another job, and the nurse knew well about it.

This time I reported the poor care the patients were getting to the certification team in Santa Fe. They came and found all I had reported was true. One of the nurses on the unit stated that the only reason that they had passed inspection before was because the certification team did not inspect and because the charts were full of lies. By this she meant that charts were falsified and treatments and meds were charted as given, even if they were not. This nurse, even after administrators knew well how poorly she performed, was later assigned supervisor of the unit. Again I reported it to the inspection team. They came and recommended this nurse be relieved of her duties as supervisor—and she was not at the beginning; finally she was. Conditions on the unit continued to get worse. And I was the one that was getting blamed for the poor morale. And I was put under the supervision of LPN's again and under the supervision of attendants for two nights.

They moved me and assigned me to give in-service to attendants. I was giving in-service to attendants while an LPN was giving in-service to RN's. They were warned about this by the board of nursing but they didn't do anything about it. It was still the same way. This LPN was given a letter of commendation for giving a crash in-service to attendants during the inspection we had for the investigation. If she had been doing her job all along, there should have been no need for a crash program.

I had been transferred from teaching attendants in July. I told them that if the nurses did not make themselves responsible for following up on the in-service given attendants and make sure they performed as they were taught, there was no point in giving inservice to attendants. They keep on doing as they wish instead of taught because nobody cares what they do, and the nurses themselves give them a bad example.

I have been reporting the poor quality of care the patients were getting at the State hospital since 1979 to officials in the central office in Santa Fe, to the State board of nursing, to the attorney general's office, to the certification team, to the local district attorney, because he was so concerned about some cattle that were apparently not being fed or watered, and, finally, to the human services department, because they were so concerned about child abuse. They were ready to start investigating, but when Mr. Goldberg came into his office he put a halt to it. I really believe that if the news media had not been in the process of investigating the hospital themselves, the investigation by the State would not have taken place There were no firings nor any blame was put on anybody. It is a shame they had to spend so many thousands of dollars on the investigation when they could have well used it to take care of patient care.

They never asked me anything when they came to investigate. I would have been able to give them the same recommendations that they found, the same problems that they found.

[The prepared statement of Ms. Lopez and information follows:]

TESTIMONY OF:

HELEN LOPEZ, R.N.
ALBUQUERQUE, NEW MEXICO

HEARING BEFORE THE
SENATE SUBCOMMITTEE ON THE HANDICAPPED
and APPROPRIATIONS SUBCOMMITTEE ON
LABOR-HHS-EDUCATION AND RELATED AGENCIES

APRIL 3, 1985

I started to work at the New Mexico State Hospital in April of 1977. After a month I was appointed supervisor of the acute medical and surgical unit and advised to get the unit ready for certification. One of the officials from the main office in Santa Fe was very upset with the director of nurses because she had not done anything at all to improve conditons during the several years she had been DON.

Besides performing the daily duties as supervisor, I had to do all the paperwork that was required; nursing care plans for every patient we admitted and procedures for carrying them out; up-date the policy and procedure manual; outline the inservice to be given for the staff and make out the lesson plans for this inservice; make job descriptions for RNs, LPNs, and attendants working in the unit. I was offered no help so I had to do most of the paperwork at home. Medical Service passed inspection after one month of preparation. I had problems because the RNs, Lpns, and attendants wanted to do procedures their way not according to the Nursing Manual. Because I was trying to initiate the following of proper procedure and because of their refusal to do it, I started finding myself before the union on a weekly basis. Valuable time I could have used to do something for the patients I had to spend trying to defend myself from administrators, DON, union leader, and attendants. That was to be my way of life here. In this unit I saw an unexplained fracture and a dislocated shoulder caused by improper handling, very painful.

After the above unit was certified, the administrators decided they could "make more money" if the Pond.1 unit was turned into a Skilled Nursing Unit. They wanted the money but little did they think of the requirements to keep the unit certified. (The care of those patients already in this unit should have been getting skilled nursing care even if it was not a requirement). They were not being turned, they were not gotten out of bed, they were getting even less than assembly line care. None of the nurses wanted to be supervisor of this unit. I volunteered because knowing the attitude of some of the nurses I did not want them to say "I did not ask for this" and the patients would have to pay for it.

Again, I did not get any kind of help from anyone. Instead, between the administrators, DON, nurses and attendants I was being undermined in my efforts. What I asked the attendants to do the nurses told them not to and encouraged the attendants to report me to the union, which they immediately did.

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The cases of patient abuse have been submitted already but there was abuse by neglect, harsh handling on a daily basis. There was no oral care. The patients were always bruised and we had several patients with dislocated shoulders because the attendants refused to use turn sheets for turning. Many of them had arthritis and they hurt when turned. They got no medication for it. Only one man that I know of received medication for his arthritis and that was because he was alert and the relative of one of the administrators. I kept telling the administrators that the reason attendants hated to do their work was because They were not made for this kind of work. The attendants would tell me they hated the patients, the only reason they here was because they could not find any other kind of work. The administrators and nurses had been here so long they did not/know any other kind of care that should be given the patients. They did not for one minute consider any aspect of the patients' feelings, comfort, or physical pain. Low moral was caused because only a chosen few were ever recognized for achievement whether they deserved it or not, or for just doing what they were supposed to do.

I was transfered to the Zias, a unit for the mentally retarded, also a ward where they sent staff for punishment. I was told they were having trouble with missing narcotics; the patients were losing weight and the ward smelled very bad. The conditions I found were deplorable. It was filthy and smelled worse than a barn. The patients were not even getting custodial care. They had more than enough staff but the staff would stick together in one place and the patients wondered around the ward ad lib. If a patient got hurt no one knew how. One patient woke up' with a fractured leg one morning; one badly beaten; I called the director, who did not come; I called the director of nurses who came after the security had come and taken pictures. The director of nurses came and she tore up the pictures and the incident report I had written and the notes I had entered in the patient's chart. Because they would not allow/me to/do anything about improving the conditions, I reported all of this to the M.D. in charge of mental health in Santa Fe. because of this I was put under the supervision of LPNs. Eventually I was transferred again to get me out of the way. Nothing was done to improve patient care.

In the alcoholism unit I was again placed under the supervision of an LPN, who did go to RN training but could never pass her state boards. This nurse took care of a patient with a rectal temperature of 100, which would be 99 if taken orally. She charted she had given the patient a cold sponge and opened the windows on one of the coldest nights of winter. Nurses had the habit of giving the patients aspirin any time they asked for it. One time we had a patient who war allergic to aspirin. I taped a warning on a tape on the medication door so no one would give him aspirin. The above nurse did not like that idea so she took this tape off the door. The very night the patient received aspirin and landed in the hospital with an allergic reaction. The attendants on this unit were allowing the patients to drink and just because I was reporting this they threatened to beat me up,and put sugar in my gas tank and broke my windsheild. All this done to get rid of me because the DON had assigned me to the medication team, an idea of hers that violated all the Rs in the rules for giving medications. This team was to give medications hospital wide. It was obvious they were not going to give medications on time. We did not know the patients and the ward staff were very uncooperative in giving us any kind of information; we did not observe the affect the medication had on the patient; we did not take the orders off the chart. We were doing everything in the dark. Once I was supposed to give phenobarbital to a patient I could not even arouse. I did not give it and advised the staff to check on her and advise me what the doctor wanted to do. I could not get ahold of the doctor myself, but I had to go on. The next day the director on the unit got after me for not giving it even though they were still having trouble arousing her. Another patient on this same unit came to me and asked me for her lomotil. I saw that it had been given to her every time the team came by. I asked her if she had diarhea yet and she said yes. I asked the staff and no one knew so I told them to observe her closely and if she did they should notify the doctor because after all that medication she should not have any and the doctor should look into it. Apparantly nothing was done. This patient was later transferred somewhere else where they found she was full of intestinal cancer. She got lomotil all the time she was here.

The narcotics were being kept in rooms where attendants had a key to. Patients were not getting their medications if they were not in the unit when the team came by. I advised the director of nurses of all the irregularities several times and nothing was done. I finally told her I was going to report this to someone who might do something about it.

Again, the DON found it easier to transfer me than to correct all the irregularities I had pointed out to her. She assigned me to skilled nursing again, the unit she had me from before. Now, they had 3 times as many nurses and twice as many attendants as when I was there but the patients were not getting any better care. They told me that they moved me because they were so short of help. They had hired a nurse that was supposed to be an authority on PSRO and certification needs. She did not know anything and did nothing. She was hired as a Nurse V and a very high salary. Her way of handling problems was "I don't want to hear about it". That was supposed to end the problem. The reason they considered themselves short was because this nurse V had allowed the supervisor of the unit go on two weeks of "sick Leave" The supervisor was really in Florida looking for another job and the nurse V knew well about it

This time I reported the poor care the patients were getting to the certification team in Santa Fe. They came and found all I had reported. One of the nurses on the unit stated that the only reason they had passed inspection before was because the certification team did not inspect and because "the charts were full of lies". By this she meant charts were falsified and treatments and meds were charted as given even if they were not. This nurse, even after administrators knew well how poorly she performed was later assigned supervisor of the unit. Again I reported it to the inspection team. They came and recommended this nurse be relieved of her duties as supervisor. She was not. Conditions on the unit continued to get worse. I was being blamed for everything..."poor morale" I was put under the supervision of LPNs again, and under the supervision of attendants for two nights.

They moved me and assigned to give inservice to attendants....while an LPN was giving inservice to Rns. They were warned about this by the Board of Nursing but they did nothing about it. It is still the same way. This LPN was given a letter of commendation for giving a crash inservice to attendants during the inspection we had for the investigation. If she had been doing her job all along there should have been no need for a crash program. (I had been transfered from teaching attendants in July. I told them that if the nurses did not make themselves responsible for following up on the inservice given attendants and make sure they performed as they were taught there was no point in giving inservice to attendants. They keep on doing as they wish instead of as taught because nobody cares what they do, and the nurses themselves give them a bad example.

I have been reporting the poor quality of care the patients were getting at this hospital since 1979 to: Officials in Central office in Santa Fe, to the State Board of Nursing, to the Attorney General's office, to the certification team; the local district attorney, because he was so concerned about some cattle that were apparently not being fed or watered; and finally to the Human Services Department, because they were so concerned about child abuse. They were ready to start investigating but when Goldberg came into office he put a halt to it. I really believe that if the news media had not been in the process of investigating the hospital themselves the investigation by the state would not have taken place. There were no firings nor blame put on anyone because they would have had to start with themselves. It continued cover-up and denying it was as bad as it was.

It is a shame they had to spend so many thousands on the investigation when they would not have had to pay a cent if they had come to me I would have told them where all the problems were. They did not ask me a thing. I would have been able to give them the same recommendations Ms. Scarfiotti did $11.00 an hour instead of $55.00 an hour. I had certified two other units already and spelled out a good program for another. All that money they could well have spent on improving the programs they have for the benefit of the patients instead of for the benefit of the friends of officials that ordered all the investigations.

The sad thing is that the new administration started out doing the same thing the previous administrations did, recognizing and honoring and giving credit where it is not due.
I had reported all the deficiencies to our personnel director many times, she blamed me. She gets honored as a leader. Ralph Gonzales, R.N., was Director of Nurses of the units they almost closed up; Connie Kemm, was assistant to Mr. Ray Crespin, and was following in his footsteps to perpetuate his administrative policies; Tita Uliberri was assistant director of nurses even though she is not a nurse, ahd was behind the DON who had no ethics nor morals. This starts creating or continuing moral problems.

In this place, more time and energy is spent on making life miserable for those they do not like than in concentrating their efforts on patient care. Much money has been used on advertising for nurses and doctors and when they come if they are too much of a challenge for administration they immediately start to try to get rid of them by lying and trying to get others to lie for them.

Submitted by Helen Lopez

1976 I prepared the Skilled Nursing Unit for certification. 37 patients. Had only 2 RNs, 4 LPNs, few attendants for 24 hours. For 3 months I worked 2 shifts with few days off, once I had to work 24 hours straight because they refused to give me help. Administrators and director of nurses insisted there was no work to be done there. LPNs and attendants were never told why they had to do what had to be done. I was considered a "poor supervisor and bad employee" because I was trying to insist the upgrade of nursing standards and quality patient care.

I have seen:

Many patients not being fed. - because of laziness.

Abuse by neglect, carelessness, teasing, lack of consideration, sheer apathy, and assault and battery!

✓ On the Skilled Nursing Unit: Patients not turned as often as they should. Left sitting in one position as long as 6-7 hours.

Exposed to very cold temperatures with nothing but a thin gown and a sheet on them.

Not fed.

Left on dirty, wet wrinkled linens for long periods of time.

Mary [redacted] died of cancer..Had hard mass in abdomen. Complained of much pain. Doctor kept saying it was a "hernia". Had no appetite. No medication for pain, nothing done until she had hematemesis. Had surgery, very sick, died.

Carol [redacted], had femur broken; was in much pain; no splint applied, no traction applied. no medication ordered for pain. No cast. Lived in that condition for about a month.

Ella [redacted] developed thrombosis in upper left leg. Toes, feet, lower leg started getting gangrenous. Nothing done by ward doctor. Had to call another doctor to do something. Surgery done to amputate. Patient died within a month.

Many incidences of urinary tract infections because of lack of proper care; not secured in place. When pulled did much damage to the bladder lining causidg much pain, bleeding and infection. Many times pulled out with bulb intact causing even more pain and damage.

Problems with the gastric tubes because LPNs refused to secure them in place according to proper nursing care; intestines by peristaltic motion "swallowed" the tube and when pulled out caused much pain and bled. Once, Lee [redacted]'s tube was swallowed and he passed it out per rectum three days later.

Tube feedings were put up in 1500cc containers to save time. They either went too fast or too slow; sometimes in a matter of 20 minutes. In one month 4 patients died of aspiration pneumonia because the enormous amount of liquid in their stomach backed up into the lungs. A doctor agreed with me it was dangerous practice but nothing was done about it.

A psychiatric patient brought to this unit with no plan of care, no follow-up by psychiatrist, treated lenient by one shift so he would not bother them, and harshly by another to punish him. Once put in restraints without an order, without being checked, without being reported. When I found him restraints were on so tight we had to cut them off with a scissors.

Mr. Lowell [redacted] beat up badly by an attendant I had been wanting to fire (that I opposed his assignment to our unit because he was an alcoholic that appeared to be under the influence of alcohol all the time).

Another attendant I had been trying to get rid of for drinking while on duty left a patient in the whirl pool unattended and if I had not been checking he would have drowned. This attended transferred to another area and subsequently fired for patient abuse.

Another attendant I had been trying to get rid of because he refused to do as ordered scalded a patient from the waist down and instead of reporting it he took it upon himself to peel the skin that blistered until I noticed. (Another LPN was in the room and had not even noticed.)

(Just before I started working on this unit I was told that one LPN was feeding a patient through the naso-gastric tube and had not even noticed the patient was dead.)

One of the LPNs under my supervision purposely told the attendants not to do as I said. She told them to report me to the union for trying to get them to give the patients the care they should get. (I was not even allowed to give this LPN a letter of reprimand for insubordination)

Foley catheters were not changed as frequently as they were supposed to. They would get stuck inside the bladder. This happened to Mr. Isidro Montoya once. The doctor tried to forcibly pull it out. It was very painful for the patient; nothing was given for this pain. The catheter was also plugged and patient was also uncomfortable, in pain, because of a very distended bladder. This was a 0900. At around 1030 he was transferred to a hospital 60 miles away, in the hospital ambulance. This ambulance broke down 20 miles out of town. This patient did not get to the other hospital until 1300. They were aware of the condition since the night before. Can you imagine the pain and suffering this man went through, and nothing was given for pain.

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The same thing happened to Mr. Hugh [redacted]. At 1500 it was reported to me he could not urinate and that he was being sent to this hospital 60 miles away at 0900 the next morning. When I checked him he looked like he was about 10 months pregnant from the distension of the bladder. I immediately called the doctor and told him it was necessary to send this man to Santa Fe right now. They did surgery on him as soon as he got to the other hospital.

Evangeline [redacted] had to have major surgery to have a removal of fecal impaction. This because the LPN on duty did not order her attendants to give her an enema on Friday night nor Saturday, nor Sunday, because it was a week-end.

Sylvia [redacted]'s lower leg was fractured while being lowered into the whirlpool at around 1000. Doctor not notified until 1400. Reports are she did not get anything for pain.

Miqualita [redacted], attendants reported to LPN on duty her leg appeared to be broken. LPN said it was not. Next day the family complained about the appearance of their mother's leg. Dr. put traction on it. Three days later it had to be amputated because of the damage that had been done by no care and improper care.

✓ Michael [redacted], totally paralyzed, positioned improperly, suffocated. Nurse told attendants not to report what happened — because of the consequences. Report was he died of natural causes.

[illegible]

LPN on duty was allowing attendants to insert foleys and naso-gastric tubes, much against nursing law. This same LPN threw medications and feedings down the drain instead giving them to the patients. She was protected by director of nurses, supervisors, administrators. She had time to play cards fpr 2-3 hours at a time even when she was the only nurse on duty.

Mary M[redacted], leg had to be amputated because of an infection on the heel bedsore; due to neglect.

Solomon [redacted] the same as above but got beat up by an attendant as well.

Benjamin G[redacted] practically rotted to death. He was severe pain even to touch. When the doctor debrided him he did not even give him anything for pain. We had to beg the doctors to give him anything for pain, then they would order it prn and nurses did not bother to give it.

Rebecca [redacted]' right leg was broken at around noon. Doctor did not see her until 1900. Nothing was done for her and I had to beg for an order for medication for pain. She was mentally retarded but would moan loudly as if in pain, more so when turned. Nothing done for it today, one year later.

[redacted] about 30 years old fell and hit her head causing a laceration that was about 4 inches one way and another 3 the other. She was walked from her unit about 3 blocks away, at night, to where she was to be seen by the doctor. The doctor gave her 1 cc of 1% lidocaine to anesthetize the area before he sewed her up. This was hardly anything. We could harldy keep the girl on the table between three of us and the doctor was very upset with her because she would not be still. It was a deep gash.

[redacted] was brought to the acute medical unit with a very distended abdomen. The doctor diagnosed it as a paralytic illeus. The doctor made frantic calls to the town surgeon. He was not in town. He was non-the-less scheduled for surgery in the morning. I checked him for impaction after the doctor left and he was impacted. I called for permission to give him an enema. I had to manually disimpact him before I could give him an enema. After we had cleaned him out he did not require surgery any more.

An LPN in one of the psychiatric units called me one evening and told me something was wrong with one of her patients...he couldn't breath. I asked her to call the doctor immediately and describe to him what she saw and if she thought it safe to send to the acute medical unit to get him there in a hurry. When the patient got to our unit he was very cyanotic, very delirous, incoherent, had a rash all over, his neck glands were very swollen, and his tongue was very swollen. I figured he was having an acute allergic reaction to a medication. He was having difficulty breathing and I got the everything for an emergency intubation because of all the swelling in his throat. When the doctor came he was very upset because the patient was so uncooperative and put his stethoscope on the desk and told me he was going home and when he quieted down to let him and he would come and examine him. He left. I called another doctor who was not on call. I told him I needed help right now. He told me to call Dr. Terr back. Dr. Terr had told me the diagnosis was "acute manic reaction". I had shown Dr. Terr the PDR where it showed that all we saw in this patient was an acute reaction to one of the medications he was taking. Dr. Terr only threw the book back at me. At this point I called the pharmacist and reported what my situation was. She called Dr. Macaluso and told him something had to be done quick. He told me to call Dr. Terr again so I did. Dr. Terr told me to give him adrenalin I.V. I could not get anywhere close to him much to his vein. I called the pharmacist again. She called Dr. Macaluso again. He came very reluctantly. We worked on that patient for three hours before we saw any sign of improvement. The pharmacist told me my efforts saved this man's life. The doctors wanted to have me fired because I called Dr. Macaluso, who was not on call and I called the pharmacist. If I had not been there that patient would have died because no other nurse would have dared to go over Dr. Terr.

Hazel D[redacted] was brought to the acute medical unit very badly battered. She had been attracted to a married man in the unit she was in, the geri-psychiatric unit. Because of this they moved the man to another unit and Hazel wanted to commit suicide. [illegible]

According to her chart she was put in seclusion at 2100. She was not checked until midnight when they found her all battered up. They claimed she did it to herself. I could not see how she could get some of those bruises on herself.. Her face was all swollen, her eyes were black and swollen, neck was all bruised. She almost died on us this time. She got better and was sent back to her unit. A few days later she came back to our unit even worse than before, and a large hematoma on the back of her head she did not have before. She did die this time.

It was reported by staff on the unit that Eileen [redacted] did die of a urinary tract infection not properly treated. (Dr. Terr)

[redacted], an alcoholic with a severe asthmatic attack was reported in "good condition when I got report a 1500 by the supervisor of the day shift. I immediately made my rounds and found this man in acute distress. I called the doctor and he worked with him for three hours before he showed any signs of relief. One attendant told us he was like that before we came on duty. I happened to hurt my back trying to straighten him up into a position that would help his breathing and the supervisor refused to sign my incident report because "there was absolutely nothing wrong with that patient."

Mr. Orvil [redacted], had acute attacks of asthma; one morning we came on duty and I could hear his labored breathing as we came on the ward, and his room was at the other end of the hall. I went to check on him and he was quite sick. Beverly Emott, R.N. was in charge so I told her she better get ahold of the doctor right away. It so happened I had to go to a class at 0800. I returned by 1100. I could still hear Mr. [redacted] as I came on ward again. I went to check on him and his respirations were as labored as before. I asked the LPN in charge of medications what she had given Mr. [redacted] his medication for the asthma.She said she had not given him any. I asked Mrs. [redacted] how come Mr. [redacted] had not gotten anything for his breathing. She told me she had gotten an order from the doctor a 0900 but that she was not going to pick it up from the pharmacy until they came to bring the drugs. That would have been a 1500. I got the order and went to the pharmacy and gave him the medication myself. I also asked the pharmacist to come and see Mr. [redacted] condition.

For Helen Lopez +
Charles Zdravesky
[illegible]

SENATOR DANIEL INOUYE

QUESTION FOR NEW MEXICO CONCERNING THE MENTALLY HANDICAPPED

During the hearings this week, it has been repeatedly stated that there is no independent agency that monitors these state institutions therefore there is much "cover up" that occurs in the system during these inspections. If by chance there are improvements to be made, many times there is no monitoring to see if the improvements were made. What role does the state government play in inspecting these state institutions in the state of New Mexico? How is patient advocacy handled?

Senator **Weicker**. Senator Domenici has submitted a question, which I would like to go ahead and ask of you, and, I might add, if anybody else wants to respond, they may—I have not yet had Mr. Zdravesky testify.

Senator Domenici asks the following question. Over the past 3 days, the Members of the Senate Labor and Human Resources Appropriations Subcommittees have heard compelling testimony from patients and families on the conditions of institutions serving the mentally disabled.

Have there been any improvements in the conditions at the New Mexico State Hospital at Las Vegas since these problems were revealed last year?

What would be your response to that question?

Ms. **Lopez**. Senator Weicker, I have been—in July I was assigned into volunteer services, and I do not have the opportunity to say at this time whether I have seen any—I am not in nursing care area.

Senator **Weicker**. In other words, what you are saying is you were transferred out of the nursing care.

Ms. **Lopez**. Yes, sir.

Senator **Weicker**. Do you think your transfer was a result of your speaking out on these issues?

Ms. **Lopez**. Yes. Well, because of all the pressure, I do have a hearing problem. All the pressure that I was under made it much, much worse, and I developed a severe ringing in the ears that not even a hearing aid will help. And they transferred me out.

I did request at the time that they transferred me out of the nursing section to be put in staff development, quality assurance, or auditing charts. They refused to give me any of those. So they put me to do volunteer services.

Senator **Weicker**. I've got a list which you submitted to the committee of abuses that you observed. Is this an accurate list?

Ms. **Lopez**. Yes, sir.

Senator **Weicker**. From your own experience?

Ms. **Lopez**. Yes, sir.

Senator **Weicker**. Carol S. had her femur broken, much pain, no splint applied, no traction applied, no medication order for pain, no cast—lived in that condition for about a month.

Ella S. developed thrombosis in upper left leg; toes, foot, lower leg started getting gangrenous; nothing done by the ward doctor; had to call another doctor to do something. Surgery done to amputate; patient died within a month.

Benjamin G. practically rotted to death. He was in severe pain even to touch. When the doctor debrided him, he did not even give him anything for pain. We had to beg the doctors to give him anything for pain, then they would order it PRN and nurses did not bother to give it.

Michael S. totally paralyzed, positioned improperly, suffocated. Nurse told attendants not to report what happened, because of the consequences. Report was he died of natural causes.

Sylvia M's lower leg was fractured while being lowered into the whirlpool at around 10 o'clock. Doctor not notified until 2 o'clock Reports are that she did not get anything for pain.

In any event, there are just a raft of matters here which I gather but, for the most part, you saw yourself; is that correct?

Ms. **Lopez**. Yes, sir.

Senator **Weicker**. And how many years did this go on?

Ms. **Lopez**. I started working there in 1977, and all this has happened from the first day that I started working there, that I started noticing. And I was transferred in July, out of nursing care in July.

Ms. **Merilatt**. Senator Weicker.

Senator **Weicker**. Yes.

Ms. **Merilatt**. I had a woman call me when she found out I was coming here, and she said that her son was up there 10 years ago and that the conditions were very much the same. That was her conclusion, because of experiences that they had gone through with their son.

My husband took another friend of ours who has a son up there right now, up there about two weekends ago, and he said that it didn't seem to him that conditions had improved.

Senator **Weicker**. All right. Ms. Lopez, you state in your testimony that the director of nurses at New Mexico State Hospital tore up pictures you had taken of an abused patient as well as the report you had written concerning the incident.

Are you aware of any other instances when hospital officials have kept incidents of abuse from being reported?

Ms. **Lopez**. Well, we had a young boy by the name of Mark on the skilled nursing unit—he was a young boy, he was a psychiatric case, but he had bad physical injuries. And there was never a care plan written for this boy. He was in the skilled nursing unit for a long time, he was a psychiatric patient, he was able to get around in a wheelchair; and there was never a plan for care written out for him. And the day nurses would treat him more severely, the evening nurses would let him have his way and let him do whatever he wished just so that he wouldn't bother them. And I just don't know how he got out of there.

But anyway there was a case of patient abuse in regard to him. One evening I saw one of the attendants, he was on the floor, the attendant was kicking him, I called the director of nurses who was at the front desk to come and watch it. And it was right there. But at that point the director of nurses came, the attendant denied that he was doing anything. So that night, to keep from getting beat up myself that very evening, I just told them that it was up to them to decide whether they thought it was patient abuse or not. The patient reported it, the other patients that were there that were verbal said it was true. And the supervisor of the unit wrote in that boy's chart what happened that evening. I didn't, because they didn't want me to put down what I had seen.

Senator **Weicker**. Have you ever been directed by your superiors not to record incidents which might indicate abuse or neglect in patient records?

Ms. **Lopez**. Every time I reported, I got in more trouble; I got letters of reprimand, and I was transferred, put on night. If I reported anything, I was put under the supervision of attendants. They didn't want me to report anything to the patient advocate, and they didn't want me to report anything to anybody.

Senator **Weicker**. Are you aware of instances of patient abuse or neglect which led to death?

Ms. Lopez. We had one patient by the name of Hazel Dean that was brought to our unit, the acute medical unit, and she was a patient in the psychiatric area, the gero-psychiatric area, older patients with mental disabilities, with mental illness. She had developed a likeness [sic] to one of the other male patients, and just because of this they wanted to keep them separated. And she got very depressed, so she wanted to commit suicide. They put her in isolation, they put her in a locked room, solitary. And apparently from the chart they brought to the acute medical unit, I saw that they put her in at 9 o'clock. At midnight, the nurse charted she had checked on her before going home. By that time she had already banged her—they said she had done it to herself, had already banged her head on the wall, and she came into our unit with her head—her eyes were black, had bruises all over, she was very well banged up. We had her in the unit about 2 or 3 weeks, and then they sent her back to her own unit. Just a few days later she came back in in worse shape; they had done the same thing all over again. And I do believe—I was not on duty at the time that she died, but I believe that she died as a result of those injuries.

We had several incidents in which we had three patients that were brought to us from the skilled nursing unit—they died from I guess the liquids in their stomachs going into their lungs. They used to feed them in great big bags—they about 1,500 cc.'s in the bags, and 1 minute the bag was full and the next minute the bag was empty. The contents would go in the stomach and then they would regurgitate it and go into the lungs. And we had three patients that died of that.

And I reported it to the nurses, and I reported it to the doctor, and the doctor said it was very dangerous—but nothing was ever done.

And at that point in time I was transferred out of the unit, so I don't know whether——

Senator Weicker. Let me just pursue that for 1 minute, and then we are going to move to our next witness. These are three patients who were fed?

Ms. Lopez. Yes, they were getting naso-gastric feeding, the tube through the nose and into the stomach. But they were putting too much in the stomach at one time.

Senator Weicker. And is this controlled by an attendant?

Ms. Lopez. It's supposed to be controlled by an LPN—by nurses. By the nurses.

Senator Weicker. And these nurses administer the food in that fashion, too fast, to the point that the patient regurgitated or the food went into the lungs?

Ms. Lopez. Yes, the food went into the lungs, the liquid went into the lungs.

Senator Weicker. And they died.

Ms. Lopez. They died.

Senator Weicker. When was this?

Ms. Lopez. This was between December 1984 and July 1984.

Senator Weicker. December 1984?

Ms. Lopez. Yes, sir.

Senator Weicker. And when?

Ms. Lopez. July—I was transferred out of the unit—that's when I saw it

Senator Weicker. July 1984?

Ms. Lopez. Yes, sir; I was in the acute medical unit at that time.

Senator Weicker. A little less than a year ago.

I know that Senator Kerry will have questions to ask, but why don't we move to Mr. Zdravesky, listen to his testimony and ask questions.

We very much appreciate the Senator being with us. He is the new ranking member of this subcommittee, and one who has expressed a deep interest in the problems that we are hearing about today. And I might add we need all the friends we can get, believe me, when it comes time for legislation or appropriation, and I am just tickled pink that Senator Kerry is on this panel and is the representative of the Democratic Party in terms of leadership on the issue.

Mr. Zdravesky?

Mr. Zdravesky. Thank you very much, Senators, for the opportunity to address this body. My name is Charles Zdravesky.

For the past eight years I have been a volunteer at public radio station KUNM-FM in Albuquerque, NM. I am a cement finisher by trade. Since 1980 I have done investigative reports on New Mexico's prison system and now the State hospital.

Our initial investigation uncovered alleged mistreatment of patients, possible widespread neglect resulting in several untimely patient deaths, theft of hospital property and patients' belongings, misuse of Federal and State funds, incompetence in the legal system, and administrative and bureaucratic bungling and coverup. This information was gathered over a 10-week period, beginning in July 1984. It came from official Health and Environment Department documents and over 125 personal interviews. The results were aired and published in August 1984.

The 616 patients at State hospital are divided into 4 general areas. Patients with psychiatric disorders are there voluntarily and under court order, 200 patients are at the long term care division, called Meadows Nursing Home, people in the criminal justice system are housed at the Forensic Treatment Unit, and patients who are ill are cared for in the acute medical and skilled nursing units. The hospital has a yearly budget of $21 million of which 80 percent is for payroll and $233,000 for medication. That breaks down to $1 per patient per day for drugs compared to only $1.10 per patient per day for food.

Patients at the New Mexico State Hospital have been confined beyond their legal commitment period. Also, patients who have been declared incompetent have been allowed to sign voluntary commitment papers so as to bypass the legally required periodic commitment hearings. During one series of commitment hearings in the summer of 1984, attended by me, the doctor present was not familiar with the treatment of the first two patients being recommitted. In a third case, a second doctor had no knowledge of his patient's prior lobotomy and in another case the patient had to point out to his doctor that the physician had the wrong chart. The patient was recommitted anyway.

A clinical audit of hospital records, dated April 9, 1984, revealed nearly 12 percent of the hospital's patients' legal papers were not current. Also, out of 3,000 commitment hearings, only twelve witnesses have appeared in the patients' behalf.

An elderly woman patient had her leg broken below the knee in a whirlpool and the accident was never reported. When the staff on the unit noticed a problem with her leg, nothing was done. Eventually gangrene set in and the patient's leg had to be amputated. A family member has notified me that since this incident the woman has suffered a broken wrist.

In the past staff have been witnessed bouncing a large rubber ball on a patient's head, playing the piano so loud at night that patients were kept awake, and tearing up incident reports. Windows have been left open in patients' rooms and some of these patients have contracted pneumonia. Patients who have been left unattended in whirlpool baths have almost drowned. Other patients have been scalded in tubs.

Since 1979 there have been more than 20 unexplained or questionable deaths at the New Mexico State Hospital. Several nurses have described problems resulting from the improper care of nasalgastric tubes. These NG tubes have not been inserted properly or not checked regularly and patients' lungs have been filled with the fluid that was being fed through the tubes. This has possibly caused many deaths that were officially listed as pneumonia.

According to a staff memo one female patient in 1980 had her EKG "misinterpreted and she was overmedicated." On her report of death it states "she collapsed suddenly * * * only minutes after taking medication." The immediate cause of her death is listed as "undetermined."

An 18-year-old male was in a car accident in March 1981 and subsequently taken to the State hospital. Because of his head injury, he was comatose. This patient would normally lie on his back or side. He was found one morning lying on his face after he rolled over from his side and suffocated. Sources have said that the night nurse did not make her rounds that night. He died more than 2 years after his accident, but the official cause of death is listed as "head injuries with complications."

A 57-year-old male patient died of a perforating ulcer only 2 days after his release from State hospital. There is evidence that members of the hospital medical staff were aware of his condition but released him anyway. A member of the department's legal staff admitted that after this death the hospital was "vulnerable to lawsuit."

Other patients have died as a result of the lack of proper medical care for fractures or aspiration problems with gastric tubes.

Patients have been able to escape from the forensic treatment unit because the staff on duty were asleep. In the clinical audit of April 1984 it states that the majority of psychiatric history forms in FTU patients' charts are blank and treatment plans are not being prepared by professional staff. In November 1983 the U.S. Department of Justice was notified about conditions at the forensic treatment unit. The main concerns were protection of patients from harm and least restrictive environment.

Doctors at State hospital have been warned about admitting patients over the telephone, locked emergency treatment kits sometimes could not be found in emergencies and, when they were found, the keys were not available. Outside doctors who are familiar with State hospital patients admit that there are a lot of broken hips of patients. Sometimes one or two a week.

One patient at the New Mexico State Hospital was administered drugs for up to 1 month with no written order. After an incident report was filed, a medication order was made out, postdated, and inserted in the patient's chart. Nursing units have passed inspection because documents have been falsified. Supervisors have destroyed patient records even though these files were the only existing records for specific patients.

Purchases have been made from patient trust accounts with Federal and State moneys of jogging suits, color television sets, perfume, and watches. These items were bought for comatose patients. Also, slippers and socks were purchased for patients who have no legs. Most of these items were stolen.

A hospital employee was found to have opened a patient's mail, removed some money, and tore up the envelope. When this matter was discovered, nothing was done. Patient's jackets, clothing, and hospital linens are taken. In March 1979 supervisors at State hospital were reprimanded by a former department secretary for falsifying job applications.

In August 1984 the 200-bed Meadows Nursing Home was close to decertification by the New Mexico Department of Human Services. This meant that the department would not transmit $11 million in payments for the care of patients. A special complaint investigation found many unsanitary conditions, incidents where patients have been restrained in violation of a doctor's order, attendants using force to open the jaws of a patient, unavailability of physicians on call, falsification of medical records, and specifically mentions that not all patient-abuse incidents are noted on hospital records.

Recently the medical doctor on call one night at State hospital could not be reached via the hospital beeper system. An employee had to be sent to the doctor's house to let the doctor know there was an emergency at the hospital. By the time the doctor arrived at the long term care unit an 83-year-old woman was dead.

A top level medical staff member at the hospital recently prescribed a drug that was contraindicated with the patient's condition. This means that there was a possibility of the drug doing harm to the patient or the use of another drug would have been more appropriate. Also this same staff member did not order the proper blood tests done on the patient even though the patient was developing malnutrition due to not enough protein in his diet.

As late as last fall the rooms in the long term care facility, where elderly patients are bathed, had no heaters. Portable electric heaters had to be used, but their use is against Occupational Safety and Health Administration and also hospital regulations. Also the tubs were provided with only cold running water with which to bathe patients.

One internal hospital memo, dated October 25, 1984, describes how the hospital emergency generator failed during a test and many units of the institution were without electrical power. These areas included the skilled nursing wing, admissions area, and the administration building.

In January 1985, a 27-year-old patient died only 6 days after being admitted to the hospital. The official cause of his death is listed as heart attack. There is evidence that the lithium levels in his blood were not monitored properly, possibly causing his death.

There continues to be indications the officials at State hospital are using the forensic treatment unit at the facility to house problem patients. Recently, a 70-year-old patient was transferred to the forensic treatment unit due to lack of bed space in other units. When this elderly patient continued to be unmanageable, he was locked into a maximum security cell. During this time the patient's legal commitment period ran out. In spite of this, he was confined for a period of time in a barred cell without a proper recommitment hearing. Top-level management in Santa Fe were aware that this was happening.

The examples I have just cited are the most blatant incidents of patient abuse and neglect. Many, many others add up to a daily lack of proper care. If the Senators have any questions, I would be happy to answer them to the best of my ability.

Thank you.

[The prepared statement of Mr. Zdravesky follows:]

TESTIMONY OF

CHARLES ZDRAVESKY
KUNM RADIO
CAMPUS & GIRARD NE
ALBUQUERQUE, NEW MEXICO

HEARING:
APRIL 3, 1985
UNITED STATES SENATE

UNM
THE UNIVERSITY OF NEW MEXICO
ALBUQUERQUE, NEW MEXICO

Thank you very much Senators, for the opportunity to address this body. My name is Charles Zdravesky. For the past eight years I have been a volunteer at public radio station KUNM-FM in Albuquerque, New Mexico. I am a cement finisher by trade. Since 1980 I have done investigative reports on New Mexico's prison system and now the State Hospital.

Our initial investigation uncovered alleged mistreatment of patients, possible widespread neglect resulting in several untimely patient deaths, theft of hospital property and patient's belongings, misuse of Federal and State funds, incompetence in the legal system, and administrative and bureaucratic bungling and cover-up. This information was gathered over a ten-week period beginning in July 1984. It came from official Health and Environment Department documents and over 125 personal interviews. The results were aired and published in August 1984.

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The examples I have just cited are the most blatant incidents of patient abuse and neglect. Many, many others add up to a daily lack of proper care. If the Senators have any questions I would be happy to answer them to the best of my ability. Thank you.

Charles A. Zdravesky

Senator WEICKER. Thank you very much. First of all, I want to commend you for what in effect is a tremendous piece of volunteer work on behalf of our institutionalized citizens.

Mr. ZDRAVESKY. Thank you.

Senator WEICKER. In your statement you note that you have also investigated prisons.

What differences did you find in conditions between the prison and the State hospital?

Mr. ZDRAVESKY. Well, Senator, I have gone into the New Mexico State Penitentiary many times—and I am sure a lot of people in this room know that is the prison that had the riot in 1980. I personally feel that the patients at the State hospital are in a more hopeless situation than people incarcerated in the State prison. A lot of the people are there because their family members don't want them, and they are basically left to the whims of the staff. People in prison, as we all know, can file any number of lawsuits and can cause a lot of publicity in the media to publicize their situation.

I personally feel that I would rather go into the State prison any time than into the New Mexico State Hospital, because it's a lot more depressing.

Senator WEICKER. Your 1984 investigation of New Mexico State Hospital revealed that New Mexico State officials received numerous reports of abuse at the hospital as far back as 1979, but the State's top health official only initiated a public investigation of the hospital in 1984, after your investigative findings were released.

Are you aware of any recent changes made at the State level to ensure prompt investigation of allegations of abuse and neglect?

Mr. ZDRAVESKY. Yes, I am. I believe there is a representative of the State of New Mexico here, and they have handed out a five-point plan talking about exit interviews—and, yes, I am aware of that. Both Governor Toney and I, of New Mexico, and the Deputy Health and Environment Secretary have said on the record that we did our investigation and that did cause the other official investigations to happen subsequently.

Senator WEICKER. Do you think it's too soon to evaluate whether or not they mean what they say?

Mr. ZDRAVESKY. Yes, I do. I believe, according to their news release, that program was just instituted about a month ago. I personally would be pretty optimistic about seeing what happened—but, yes, I do think it would be too soon.

Senator WEICKER. Do you intend to follow up within whatever you deem to be a reasonable period of time to see whether changes have been instituted?

Mr. ZDRAVESKY. Yes, I do; I am certainly going to stay on top of this story.

Senator WEICKER. Senator Kerry.

Senator KERRY. Thank you very much, Mr. Chairman. First of all, if I may, for the record, state that I personally regret very much my inability to be here the prior two days, as the ranking member, but I was unfortunately ill and unable literally to get out of bed.

I am very pleased to be able to be here today, pleased to be able to assume the position of distinguished Senator Jennings Randolph, who I think served extremely well in this capacity, and in whose footsteps I would hope to be able to follow.

And, second, I would like to express my admiration and respect and gratitude to the chairman, Senator Weicker, for having these hearings. He is someone who I think, as I have observed outside of the Senate over the years, has always been willing to put himself on the line for difficult causes at times, and not always with the greatest receptivity within his own party, for which I admire him.

And I would thank him for holding these hearings and for giving the country this opportunity to examine what regrettably has been examined before—and so finally, as we realize that, I would also like to express my own appreciation and respect for all those of you who testified today, and who have testified in these last 2 days. I followed the testimony, notwithstanding my inability to be here. And, needless to say, for those of you who have been here and listened, those who have heard from afar, as well as for those who have testified, it is not an easy process to recognize that in 1985 in the United States of America this is the way that some human beings are being treated over the protestations of those who have been made responsible for that treatment—and I think it's a tragedy and an enormous contradiction, if you will, with all the things that we hold close to ourselves and aspire to try to achieve, and to be, as public people and just as people, to recognize that homes that are supposed to be filled with hope and that are supposed to improve the human condition are for many people citadels of despair and places which in a sense reek a kind of deprivation of spirit and opportunity for people who are most in need.

I think these hearings are terribly important, and I congratulate all those who have taken part in them.

Let me ask you, if I may—and any of you can answer this, I suppose—but in Massachusetts I can remember 20 years ago visiting the Freneau State School and going into what was called the north wing there and seeing things that at that point in time I thought perhaps only Charles Dickens wrote about.

Since then, we in Massachusetts have undergone a process of deinstitutionalization, and we have reduced our 13 or so mental institutions down to some 7. We have gone from about 20,000 institutionalized patients down to about 2,200, and in recent days, as recently as yesterday and the day before in the news that that process has been inadequate, that still there are abuses, even in community-based facilities, and still there are inadequacies and abuses within the institutions.

So my questions to you are really several. And let me begin, if I may, with your testimony, Mr. Zdravesky.

Let me come at this from a number of directions. First of all, why do you think it is that whether people are in an institution or whether they are in a community-based facility of some kind or another—and perhaps you haven't experienced that yet—why do you think it is that these people are receiving this kind of treatment? What's your reason for it or your understanding of it, as you have perceived it?

Mr. ZDRAVESKY. I think there are probably two reasons in New Mexico. The first one is that there are probably not enough qualified people to do the job; and the second one is New Mexico is a comparatively poor State and doesn't have the funds to have programs that are needed.

Senator KERRY. You think it can be reduced to that?

Mr. ZDRAVESKY. Well, yes, I do. I think it is more of a complex problem, but those are probably the two main reasons that we found in our investigation.

Senator KERRY. Are you aware of any special efforts that have been made with respect to New Mexico and its relationship to Health and Human Services to try to address this need?

Mr. ZDRAVESKY. Well, let me say that since our investigation was released in August of 1984, there's been a lot of pressure on New Mexico State government, and I believe that they are probably moving in a direction which will clear up some problems. Hopefully it won't be just centered around the State hospital in Las Vegas, but will include community treatment programs.

Senator KERRY. What actions specifically—I'd like to kind of trace this a little bit. When you first became aware of this, you first led with a newsstory?

Mr. ZDRAVESKY. Well, we spent all last summer interviewing over 125 people and going to the State hospital several times, and we released it in three medias. I did 10 parts on public radio station KOB, which is the NBC affiliate in Albuquerque—did 5 parts for 1 week; then the Santa Fe Reporter newspaper did 7 parts. And we released it all at the same time.

Senator KERRY. And prior to that was there any communication at all with—how do they work it in New Mexico, is it a Sate's attorney or a district attorney, State prosecutor?

Mr. ZDRAVESKY. District attorney.

Senator KERRY. Was there any discussion at that point with the district attorney's office?

Mr. ZDRAVESKY. At the time we released our report?

Senator KERRY. Yes.

Mr. ZDRAVESKY. Well, we have been trying to meet with the county district attorney. He wanted to know if there was any criminal wrongdoing in what we found—and, to be perfectly honest with you, he's been dragging his feet. We have been trying to meet with him and he hasn't been returning our calls.

When we did release——

Senator KERRY. What's his name?

Mr. ZDRAVESKY. Arthur Bustos from San Miguel County. When we did release the report, Governor Toney and I, from New Mexico, called for a grand jury investigation, which I must admit hasn't taken place yet. The State auditor—I spoke to him about a month ago—is now doing a financial audit of the State hospital.

And I believe within the last year the State has spent about $70,000 to do various kinds of investigations of their own from anywhere to basically doing the same work we did to finding out whether the hospital could be JCAH-accredited.

Senator KERRY. And has there been any kind of contact with the U.S. Attorney?

Mr. ZDRAVESKY. Not that I know of, no.

Senator **Kerry**. Any advocacy groups that have filed any civil rights suits or taken any interest in it from that perspective?

Ms. **Merilatt**. We are considering it. We haven't formalized any action yet.

Senator **Kerry**. At this point in time, there has been no contact with them.

Mr. **Zdravesky**. As far as I know, the American Civil Liberties Union is aware of all the things that we found out, and they are considering a lawsuit, a class action suit against the State hospital.

Senator **Kerry**. But as yet New Mexico is operating its institutions without any kind of court intrusion.

Mr. **Zdravesky**. I believe that's true; yes, sir.

Senator **Kerry**. Now, with respect to the goods that you mentioned in your testimony that were stolen, has there been a specific follow-up with respect to that? I mean, there is a purchasing agent surely; correct?

Mr. **Zdravesky**. I would assume so.

Senator **Kerry**. Has that person been spoken to? Have there been any subpoenas issued? Is there a grand jury operating at this point?

Mr. **Zdravesky**. I don't believe there have been any subpoenas issued, and I also don't think that there has been a formal grand jury called. I have spoken to Governor Anaya about a month and a half ago, and he still endorses a grand jury, but I believe it might be up to the county district attorney to take that initiative—and I don't believe he's done that yet.

Senator **Kerry**. Do you know for a fact whether any investigators from any agency have been out to the hospital and have done any of their field investigation?

Mr. **Zdravesky**. Yes, I do. I believe there has been at least one investigator from the Health and Environment Department under which the hospital falls that has been to Las Vegas.

Senator **Kerry**. Nobody from a law enforcement agency?

Mr. **Zdravesky**. Not that I know of, no.

Senator **Kerry**. I have other questions, but I'll wait, Mr. Chairman. Thank you.

Senator **Weicker**. I want to thank all of you very much for your testimony. I want to reemphasize the point made by Mr. Zdravesky, because it related to my opening statement two days ago, when I said that I think all of us, to a greater or lesser degree, look opon these people not as ill or afflicted as a matter of condition, but rather we look upon them as criminals. Whether we like to admit that or not in our own minds, that is the national perception that manifests itself in the buildings, the care—and here we have the observations of one who has done investigations on both prisons and on the institution, saying he would prefer to be in the prison. That's a hell of a national evidence of compassion and care. I don't think anyone of us would stand for it for 1 minute with our child, our parents, our relatives, or our friends.

I think the uniqueness of the United States of America has been what it is that we have done for the one—the one, not the majority, but the one. And we are going to have a chance to reaffirm our national heritage here in the months ahead.

Thank you very much for your testimony.

Mr. **Zdravesky.** Thank you, sir.

Ms. **Merilatt.** Thank you.

Ms. **Lopez.** Thank you.

Senator **Weicker.** Our next panel includes two employees of institutions for the mentally disabled, Mr. Milton Baker of Syracuse Developmental Center, who has been subpoenaed here today, and Mr. Lyle Vandagriff of Metropolitan State Hospital, Norwalk, CA, who has been subpoenaed here today.

Mr. Baker and Mr. Vandagriff. Mr. Baker, would you stand and raise your right hand, please.

[Mr. Baker duly sworn.]

Senator **Weicker.** Please be seated and proceed with your testimony.

STATEMENT OF MILTON BAKER, SYRACUSE DEVELOPMENTAL CENTER, SYRACUSE, NY, AND LYLE VANDAGRIFF, METROPOLITAN STATE HOSPITAL, NORWALK, CA

Mr. **Baker.** Senator Weicker, and other distinguished Members of the U.S. Senate, I offer the following testimony about institutions for handicapped people.

For the past 30 years I have worked in institutions with the mentally ill, the elderly, and the mentally retarded. Over the past 20 years I have been active in voluntary advocacy efforts on behalf of the elderly and mentally retarded. I am also the father of two handicapped sons, both of whom live at home with me and my wife.

The institutional model is built upon an immoral, irrational system of values. Segregation and congregation of handicapped people to meet human need is both irrational and immoral. Any service system built upon such values cannot produce goodness in the life circumstances of the people it proposes to serve. Second, no amount of tinkering, money, justification, regulation, or other human effort can make such a system humane is my conclusion after all these years in institutions. The institution is an inoperable system for serving human need, and should be abandoned.

Institutionalized handicapped people are paying with their lives the cost incurred by this society's unwillingness to turn away from segregation as a service model. Handicapped people as a consequence of having to live in institutions experience what I would call a mortal wounding of their physical, social, emotional, and spiritual being. This wounding takes on many forms, some of which I'd like to share with you this morning.

No. 1, institutional settings are bereft of normalizing ideologies, processes and goals.

In human services we are experiencing an ideological bankruptcy on the part of service providers. Belief systems which undergird services often are inhumane and inoperable. This problem is exacerbated by the fact that service providers resist humane values clarification and training, and maximally humane service goals and proven humane methods are rigorously rejected by those in charge. Aspects of normalization that can be reasonably applied are seen as irrelevant, unimportant, and often perverted.

No. 2, institutionalized handicapped people experience throughout their lives relationship rupture and discontinuity.

Virtually 100 percent of the people living in institutions have no nonpaid, meaningful, ongoing human relationships with other human beings. The masses of people living in our Nation's institutions live out their lives abandoned, sometimes by their family, and abandoned by friends and neighbors, alone with no handicapped peer or true friend. This occurs as a consequence of institutionalization and is a major reason why abuse and neglect occurs.

No. 3, material impoverishment is forced upon handicapped people in the institutional setting.

Masses of people do not have even the most meager of possessions. This deprivation is one of many serious impedimenis to developmental growth, to identity building, independence, and feelings and promotion of human dignity and worth.

Being handicapped and living in an institution is synonymous with being poor. Often the very few personal possessions handicapped people have are stolen, lost, or kept in the control of paid staff.

No. 4, experience impoverishment is powerfully thrust upon people living in institutions.

Many people enter an institution never to return to the larger society again, their only human experiences defined and controlled by the walls that surround them. The varied and expansive human experiences common to each one of us in this room today—those we take for granted—will never be experienced by the masses of people living in institutions as long as they stay there.

No. 5, individuals living in institutional environments experience perpetual insecurity.

The human experience of continuous insecurity is powerfully painful. Insecurity in the institution occurs as a consequence of many factors. People have a myriad of activities imposed upon them by others without their consent, knowledge and/or involvement. People frequently are forced into proximity with others who have institutional behavior that threatens and frightens them. The institution, by its size and mission, imposes unchangeable routines, movement against one's will, and uniformity. Many institutionalized, handicapped people spend their entire lives feeling insecure about themselves and their life space. Some spend their years terrorized.

No. 6, basic human needs are not met in institutional settings.

The meeting of such basic human needs as body hygiene, personal appearance, grooming, oral hygiene, toileting, and skill development and the learning of socially appropriate behavior essential for community living cannot be taught in the institutional setting.

No. 7, there is no individualization for handicapped people in institutional settings.

Deindividualization is synonymous with institutionalization. In spite of the contemporary proclamations coming out of institutions about individualized services, there is no such thing as individualization in service. Handicapped people can tell us through their communication processes. The words such as "I," "me," "my," and "mine" are nonexistent in the vocabularies of institutionalized people. It is not uncommon for human service providers to possess very negative, even nonhuman perceptions of handicapped people.

This constitutes the ultimate in deindividualization, and justifies the atrocities presented before this committee in the last 3 days.

No. 8, handicapped people, often with severe physical and functional impairments, with needs screaming for address, always come last in the institutionalized environment.

When the needs, wishes, even whims of professionals and other paid staff come into conflict with the needs of handicapped people, the needs of staff are addressed first. When the organization has addressed the needs of staff, there often is little left in terms of human energy, commitment, and attention for handicapped people. It is virtually impossible to get rid of incompetent staff in the institutional system. Incompetent people are kept on, draining the efforts of committed, competent individuals, moving the service system to its lowest common denominator. This lowest common denominator is what every handicapped person experiences on a day-to-day basis in the institutional setting.

No. 9, the most highly trained staff in the institution spend an inordinate amount of their time fashioning and shuffling paper.

Every human problem which needs addressing in the institutional setting elicits stacks of paper. Often the paper that is generated has nothing to do with the needs of handicapped people, but rather is demanded by the bureaucracy, its bureaucrats and the functioning of the larger system in which the institution exists. Virtually every time a human need is identified, a new form, a new committee, or a new meeting emerges, all of which drains more and more time from the people who need to have human contact and interaction with the people being served. The demands of paperwork are so powerful that a professional can go through an entire career in an institutional setting with minimal contact with the handicapped people they are supposed to serve.

No. 10, the needs of handicapped people are held hostage to the politics and bureaucracy of the institution.

Bureaucratic procedures and goals, coupled with political aspirations and goals of individuals in the institution command many hours each day of valuable staff time. Often institutional politics and bureaucratic needs take precedence over the needs of people being served. Personal and department rivalry, power plays and other struggles often dominate the interactive experiences amongst the workers, while handicapped people sit and wait.

No. 11, the officers, professionals, and sometimes the consumers of institutional services are unconscious about the dysfunctionality and inhumanity of institutions.

There is a pervasive lack of awareness on the part of the functionaries of institutions and others in the society about the incoherency and dysfunctionality of the setting. Many think the institution can be made better by more Medicaid dollars—and it cannot; more staff—and it cannot; better procedures—and it cannot; more regulations—and it cannot; changes in administration; more and better inspectors, and so forth.

This unconsciousness about what we are faced with in institutions has led many to work for quick fixes of these places that are wrong at their core.

It is heresy for an institutional worker to suggest that the system is not working, that destructiveness is going on, that handicapped people must first be seen as people and only second as handicapped, that their needs must be the driving force for everyone who is working.

The good institutional human service worker is expected to keep his mouth shut, turn his head, dutifully work to keep the system rolling, and obediently conform to the dictates of authority. Once the worker transacts this role, he or she then has earned the title of the good team player.

Senator Weicker, I am not assuming the role of the good team player as I present these thoughts to you here today, and I will most certainly hear about this upon my return in one way or the other.

No. 12, and finally, and perhaps the most powerful point that I want to make, is that many would dismiss all that I have said as irrelevant, nonexistent, and even as a distortion of the truth about these places.

The institution, in the final analysis, exists in response to cultural values and mandates. Our society has mandated with the institution that these people are to be kept out of everyone's sight and mind. As long as this social mandate is being responded to through the use of the institutional model, each of us in one way or another must share the responsibility of all the inhumanity, and each of us must be prepared to pay the huge sums of money it is costing to keep this beast functioning in our midst.

In spite of ever-increasing indictments of the system, there has been a determined effort to construct more institutions in New York State. There has recently been an extremely dangerous trend in using Federal dollars to construct more buildings on the grounds of institutions. This has occurred almost secretly in contradiction to espoused consumer-sanctioned goals to the contrary This current fueling of the institutional model in New York State has been carried out with Federal assistance and guidance, a collaboration not evidenced in the much-needed deinstitutionalization arena. In the field of mental retardation, New York State consumes $500 million in Medicaid funds annually, and at this hour, while I am giving this testimony, there is very nearly $14 million in Medicaid funds being spent to construct a total of 400 more beds on the grounds of institutions in New York State. Now, those beds will be there for 50-some-odd years, and those beds will be filled.

I work in the institution in New York State that is widely known as one of the newest and best in the State. In my human service role I have applied, as best as humanly possible, the humane principles on my living units for 100 handicapped people. After this tireless 12-year effort, I must tell any audience that will listen: I do not want my two handicapped sons to ever live in an institution.

These places are wrong, they are a disgrace to our Nation. I call for a national commitment to close institutions for the retarded with the understanding that only the most courageous among us will take on such a challenge.

In conclusion, my testimony represents only the very tip of a massive, massive cultural malignancy that is among us as a nation, consuming human resource, potential, and dignity.

Senator Weicker, I offer my testimony today out of honor, respect, and love for my two handicapped sons, Timothy Baker and

Michael Baker, with a fervent prayer that they will never be dragged off to these places, where human hatred rears its ugly head, where social death prevails over life, where despair smothers out all hope, and where folly makes mockery of reason.

[The prepared statement of Mr. Baker follows:]

TESTIMONY OF

MILTON J. BAKER

TREATMENT TEAM LEADER
SYRACUSE DEVELOPMENTAL CENTER
SYRACUSE, NEW YORK

HOME: 29 WELLINGTON ROAD
NO. SYRACUSE, N.Y.

SUBMITTED TO:

SUBCOMMITTEE ON THE HANDICAPPED
APRIL 3, 1985

Senator Weicker and other distinguished members of the United States Senate: I offer the following testimony about institutions for handicapped people.

For the past 30 years I have worked in institutions with the mentally ill, the elderly and the mentally retarded. Over the past 20 years I have been active in voluntary advocacy efforts on behalf of the elderly and mentally retarded. I am the father of two handicapped sons.

The institutional model is built upon an immoral, irrational system of values. Segregation and congregation of handicapped people to meet human need is both irrational and immoral. Any service system built upon such values cannot produce goodness in the life circumstances of people. Secondly, no amount of tinkering, money, justification, regulation or effort can make such a system humane. The institution is an inoperable system.

Institutionalized handicapped people are paying with their lives the cost incurred by this society's unwillingness to turn away from segregation and congregation. Handicapped people as a consequence of having to live in an institution experience mortal wounding of their physical, social, emotional and spiritual being. This wounding takes on many forms.

1) Institutional settings are bereft of normalizing ideologies, processes and goals.

In human services we are experiencing an ideological bankruptcy on the part of service providers. Value systems which undergird services often are inhumane and inoperable. This problem is exascerbated by the fact that service providers resist values clarification and training. Maximally humane service goals and proven implementation strategies are rigorously rejected. Aspects of the normalization ideology that can reasonably be applied in the institutional system are seen as irrelevant, unimportant and often perverted.

2) Institutionalized handicapped people experience throughout their lives relationship rupture and discontinuity.

Virtually 100% of the people living in institutions have no non-paid, meaningful, ongoing human relationships. The masses of people living in our nations institutions live out their lives abandoned, alone with no nonhandicapped peer or true friend.

3) Material impoverishment is forced upon handicapped people in the institution.

Masses of people do not have even the most meager of possessions. This deprivation is one of many serious impediments to developmental growth, identity building, independence and feeling of human dignity and worth.

Being handicapped and living in an institution is synonymous with being poor. Often the very few personal possessions handicapped people have are stolen or lost.

4) Experience impoverishment is powerfully thrust upon people living in institutions.

Many people enter an institution never to return to the larger society again, their only human experiences defined and controlled by the walls that surround them.

The varied and expansive human experiences common to each of us--these we take for granted--will never be experienced by the masses of people living in institutions.

5) Individuals living in institutional environments experience perpetual insecurity.

The human experience of continuous insecurity is powerfully painful. Insecurity in the institution occurs as a consequence of many factors. People have a myriad of activities imposed upon them by others without their consent, knowledge and/or involvement. People frequently are forced into proximity with others who have institutional behavior that threatens and frightens them. The institution by its size and mission imposes unchangeable routines, movement against one's will and uniformity. Many institutionalized handicapped people spend their entire life feeling insecure about themselves and their life space.

6) Basic human needs are not met in institutional settings.

The meeting of such basic human needs as body hygiene, personal appearance, grooming, oral hygiene, toileting, skill development and the learning of socially appropriate behavior is frustrated in the institional setting.

7) There is virtually no individualization for handicapped people in institutional settings.

Deindividualization is synonymous with institutionalization. In spite of contemporary proclamations coming out of institutions about individualizing services handicapped people experience, there is little if any individualization. The words "I", "me", "my", "mine" are non existant in the vocabulary of institutionalized people. It is not uncommon for human service providers to possess very negative, even nonhuman perceptions of handicapped people. This constitutes the ultimate in deindividualization.

8) Handicapped people, often with severe physical and functional impairments, with needs screaming for address consistently come last in the institutional environment.

When the needs, wishes, even whims of professionals and other paid staff come into conflict with the needs of handicapped people, the needs of staff come first. When the organization has addressed the needs of paid staff, there often is little left in terms of human energy, commitment and attention for handicapped people. It is virtually impossible to get rid of incompetent staff in the institutional system. Incompetent people are kept on the staff roster draining the efforts of committed, competent individuals, moving the service system to the lowest common denominator.

9) The most highly trained staff in the institution spend an inordinate amount of their time fashioning and shuffling paper.

Every human problem which needs addressing in the institutional setting elicits stacks of paper. Often the paper that is generated has nothing to do with the needs of handicapped people, but rather is demanded by the bureaucracy, its bureaucrats and the functioning of the larger system in which the institution exists. Virtually every time a human need is identified, a new form or committee emerges, all of which drains more and more time from the people who need the attention of the paid staff. The demands of paperwork are so powerful that a professional can go through his/her entire career in an institution with minimal contact with the handicapped people they are supposed to be serving.

10) The needs of handicapped people are held hostage to the politics and bureaucracy of the institution.

Bureaucratic procedures and goals, coupled with political aspirations and goals of individuals in the institution command many hours each day of valuable staff time. Often institutional politics and bureaucratic needs take precedence over the needs of people being served.

Personal and department rivalry, power plays and and struggles often dominate the interactive experiences amongst workers.

11) The officers, professionals and sometimes the consumers of institutional services are unconscious about the dysfunctionality and inhumanity of institutions.

There is a pervasive lack of awareness on the part of the functionaries of institutions and others in the society about the incoherency and dysfunctionality of the setting. Many think the institution can be made better by more medicaid dollars, more staff, better procedures, more regulation, changes in administration, more and better inspectors, etc. This unconsciousness about what we are faced with in institutions has led many to confront good efforts and embrace, bad, potentially destructive causes.

It is heresy for an institutional worker to suggest that the system is not working, that destructiveness is going on, that handicapped people must first be seen as people and only secondly as handicapped.

The good institutional human service worker is expected to keep his mouth shut, turn his head, dutifully work to keep the system rolling, and obediently conform to the dictates of authority. Once the worker transacts this role he/she then has earned the title of the good team player.

I am not assuming the role of the good team player as I present these thoughts to you. I will most certainly pay in one way or another for these words.

12) The fin[illegible] most powerful problem of all is the fact that the larger society dismisses all that I have said as unimportant, irrelevant, and even non-existent.

The institution exists in response to cultural values and mandates. Our society has mandated with the institution that "these people are to be kept out of everyone's sight and mind". As long as this social mandate is being responded to through the use of the institutional model, each of us in one way or another must share the responsibility of all the inhumanity and each of us must be prepared to pay the huge sums of money it is costing to keep this beast functional in our midst.

Over the past two decades there has been much opposition to the institutional model. In spite of ever increasing indictments of the system there has been a determined effort to construct more institutions. In New York State there has recently been an extremely dangerous trend in using federal dollars to construct more buildings on the grounds of institutions. This has occurred almost secretly in contradiction to aspoused, consumer sanctioned goals to the contrary. This current fueling of the institional model in New York State has been carried out with federal assistance and guidance, a collaboration not evidenced in the much needed deinstitutionalization arena.

The millions of federal dollars that flow into New York State have made my state both the institutional and medicaid capitol of the nation.

I work in the institution in New York State that is widely known as one of the newest and best in the state. In my human service role I have applied as best as is humanly possible the normalization principle on my living units for 100 handicapped people. After this tireless, 12 year effort I must tell any audience that will listen, I do not want my two handicapped sons to ever live in an institution.

In conclusion my testimony represents only the very tip of a massive cultural malignancy that is among us as a nation consuming human resource, potential and dignity.

I offer my testimony out of honor, respect, and love for my two handicapped sons, Timothy Baker and Michael Baker.

Milton J. Baker
29 Wellington Road
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Senator Weicker. Thank you very much, Mr. Baker. I am going to come back to you for questions. I think I will have Mr. Vandagriff testify next.

Mr. Vandagriff, you are here also under subpoena, I believe?

Mr. Vandagriff. Yes, sir.

Senator Weicker. Please stand and raise your right hand.

[Mr. Vandagriff duly sworn.]

Senator Weicker. Please proceed with your testimony.

Mr. Vandagriff. Mr. Chairman, and other members of the committee, I am pleased to be here and honored that you asked me to speak on these disturbing issues.

My name is Lyle Vandagriff, I am a psychiatric technician, a graduate of California State Polytechnic University with honors, majored in the behavioral sciences, that is, psychology, sociology, anthropology, a minor in criminal justice and corrections.

I am here to talk primarily on three issues: Inadequate staffing in the mental health system; high injury rates; and communication problems in California.

I have heard a lot of testimony talking about the mental health worker. Being one of those, I would like you to please consider that most of the people who enter this field to work with the patients are not brutal, sadistic criminals that I hear so much about. Most of us came here out of concern for our fellow man, from introspection, trying to understand ourselves and our families.

The patients found at Metropolitan State Hospital are psychotic, unpredictable; they have delusional beliefs, fears of persecution, grandeur, fanatic religious beliefs. They see and react to things that aren't really there; they hear voices which give them orders that they can't resist, and they many times suffer relentless hallucinations. In the beginning, a lot of these patients are consumed with denial, they are unable to control their impulses. Eventually, from a lack of believable feedback, they lose contact with reality.

These psychiatric conditions, whatever the cause, create management problems which are at once dangerous, expensive, and frequently criminal. Profitmaking proprietary establishments, as are found in the community, cannot afford the liabilities of these particular patients in a community setting. Patients with such mental disabilities are frequently physically run down and have many communicable diseases which they bring into the State hospitals. They abuse cigarettes, coffee, alcohol, street drugs, and even the medications they receive there. They are destructive to property, they are a danger to themselves and others.

In California the patients aren't grouped according to their problems so the treatment programs can benefit the group; they are all mixed up, based on the geographical region that they are admitted from. So we have a mixture of gravely disabled patients who can't provide for their own food, shelter, or clothing, or who do things in society that are bizarre or unacceptable. Many of them are a danger to themselves; some of these are outright suicidal behaviors, and some of them are a danger to themselves because of the things that they would do that would bring some kind of retaliation on them from people in the community.

At least half of the patients that I work with are a danger to others.

The kinds of patients in the State hospital that I have observed improve the most from structured routines, often in spite of patients' rights advocates and laws which expect patients to improve from treatment that they are allowed to refuse. When patients do get better and are placed in the community, they frequently decompensate, exercising these rights, and then return to the State hospital, caught in an endless cycle referred to as the revolving door.

This revolving door is very similar to indeterminate sentencing, which is an outgrowth of the Cesare Lombroso philosophy which is based on biological determination; that is, these people are born to be this way, and that they are this way is a part of the proof, part of the stratification, that puts mental defectives at the bottom.

Recent cutbacks have reduced the quality of life for these patients. Considerably less money is available for outings and recreation. Staffing has been reduced to bare minimums. I work on a unit which has 28 beds, with 27 patients filling those beds. I have a supervisor, one person to do medication and physical treatments, and one other staff. I hear a lot of talk about negligence, but it's not like we haven't brought these things up to our administrators, and even to the politcians in California. Staffing is inadequate to provide the essential human kinds of care that they deserve. Most frequently we are blamed for this negligence. The very least is all that we have, except for an excess of management personnel.

The State of California, in preparing schedules, plans in advance to be short staffed. The code of ethics which comes with the license requires all psychiatric technicians to remain on duty until they are properly relieved. In this way, if no relief is available, staff who have worked a full shift under those conditions are then required to remain on duty, even if they have to leave children at home unattended, or face disciplinary action.

Mr. Chairman, to add insult to injury, psychiatric technicians, highly skilled in interpersonal relationships and behavioral principles, are ordered to work as janitors and housekeepers. So frequently are these duties assigned, it is now expected of psychiatric technicians, under the auspices of keeping a healthy environment. The groups they once held as therapeutic activities have been displaced by sanitation duties and administrative documentation.

I am not trying to say that those aren't important—they are. But when it comes to choosing between clean floors and giving the patients quality interpersonal care, it's a difficult decision any time.

The second element here is the high injury rate. The patient's right to refuse treatment, that is, to refuse medication, to refuse to attend groups, which would be held on their behalf, the unpredictable nature of their mental condition, and the lack of psychiatric technicians combine to create emergency conditions.

Patients injure other patients much more than they injure the staff or themselves. Of course, the patient's right to confidentiality prevents the release of specific information, but in January this year, 59 patients were assaulted by other patients compared to 22 aggressive acts toward staff, about a 3-to-1 ratio.

Here I have a graph I just sketched—I'm sure I could have done better if I had spent more time—but I think it shows pretty well. In the middle here we have injuries of the staff, and you can see a dramatic increase of injuries of the patients. I will leave this to be a part of the record—you can look at it.

Our conditions have continued to deteriorate in the last several years in spite of wide public—well, a lot of information about 10 years ago that brought to the public's attention the atrocities that were taking place in our mental health system.

The industrial injury statistics show a normal amount of standard industrial-type injuries. The addition of patient-related injuries at such high numbers and the degree of injury when one is battered explains the excessive costs of worker compensation and industrial disability leave at Metropolitan State Hospital. These employee injuries have cost taxpayers over $2 million every year—and that is based on the figure some 3 years ago, which are about half of what they are now. And at a 3-to-1 patient injury rate, $6 million more for the care of the patients 'injuries. It would be cheaper to put more psychiatric technicians on the floor with the patients.

Mr. Chairman, the behavior of these patients, were it not for their mental condition, would frequently be considered criminal when they attack other patients and staff. Unless the patient or staff becomes maimed or loses a limb, the attack is only considered a misdemeanor. And these charges are dropped by the district attorney.

If the patient attacks a hospital police officer, however, this crime is a felony and criminal charges are brought against the patient, which moves the patient to a more secure environment, a jail, but only temporarily. After the preliminary hearing, the patient is returned to Metropolitan State Hospital, and this has proved inadequate to protect psychiatric technicians.

Working under conditions such as these is made worse by disciplinary management technique. Due to such short staffing, employees are unable to schedule time off, earned for working on holidays and weekends. When psychiatric technicians use more sick leave than the quota of 16 hours per quarter, they are counseled, merit salary increases are denied as well as transfers and promotions. The requirements of the job are clearly more than a person can do, particularly when the patients are resistive and refusing treatment.

Here I would like to stop and talk about—we have found that most of our assaultive incidents occur when the staff has to demand compliance from the patients—the No. 1 cause of the assaultive situation. It's not the only cause.

But at some point in the patient's care, someone has to follow the doctor's orders, and that is the mental health worker, the psychiatric technician, or nurse, whoever is there to carry out those orders.

Patients refuse to get out of bed, they refuse to wear clothes, they refuse to get dressed, they offer all kinds of obscenities—a gentleman can't repeat the things that they say. And it's a very difficult thing to be able to cope with in that work environment.

Certainly I don't expect someone off the street to be able to work in this frustrating environment.

Emergency conditions at these minimum staffing levels leave the employee vulnerable to supervisor claims that they have left work undone and have been negligent. Burnout and stress, with such high injury rates, generate a condition very similar to battle fatigue. We know we are going to get hurt; we just don't know when.

Third, I would like to talk about communication problems.

Mr. Chairman, the patients at Metropolitan State Hospital come from every walk of life. Many are bused in from other States by families who cannot afford to care for them, even by mental health systems. Many are drawn by the lure of Hollywood, the mild climate, the dream of jobs, or just hoping to blend in. Many have heard of riches in California's welfare system.

And I would like to say this about our developmental services, that they don't seem to suffer the same mismanagement that the mental health system does.

Los Angeles has an international cross-section who suffer from culture shock trying to successfully adapt to the American urban and suburban lifestyle. None are equipped to compete in the free market for jobs, housing, medical care, or food.

But not only can language be a barrier to communication, also cultural experiences. The psychiatric technician is aware of these cultural aspects as they pertain to growth and development, identity and behavior. The psychiatric technician learns to relate to the patient, to see them as a person, someone beyond those behaviors that is worth their time, if they can reach them, in hopes of exploring experiences in search of a common ground upon which to build understanding, and if none are found to create the experiences necessary for communication to take place. Understanding the statements of psychiatric patients can be very difficult. Doctors and other clinical staff have trouble conducting examinations and tests when they cannot communicate with the patient.

Gunnar Myrdal in 1944 wrote "An American Dilemma," and he said so eloquently, discussing the thrust of medical arguments about human nature:

> They, medical professionals, have been associated in America as in the rest of the world with conservative and even reactionary ideologies. Under their long hegemony, there has been a tendency to assume biological causation without question, and to accept social explanations only under the duress of a siege of irresistible evidence. In political questions, this tendency favored a do-nothing policy.

The American school of psychology, born out of measuring the volume of skulls, called craniometry, of Paul Broka—they haven't advanced much further even with today's modern statistics. These numbers they hide behind are not much more than the emperor's clothes.

When clinical staff have difficulty speaking the language of the patient, communication certain can break down completely. Since so many of the doctors at Metropolitan State Hospital have difficulty with English, they must rely on psychiatric technicians to explain the treatment to the patient. Some of the doctors can't practice anywhere else until they become certified in basic English. And I don't think anyone here thinks that such a rudimentary skill is adequate to practice psychiatric medicine.

Too many of our medical profession are little more than sorcerers' apprentices handing out medications as the sole form of treatment, relying on the drug companies.

Professional stratification is based on a medical model and has displaced the psychiatric technician trained in the behavioral model. The legal language which provides funds to assist and care for the mentally disabled has excluded the psychiatric technician and replaced us with registered nurses. There are few of us and we don't have a powerful lobby like the doctors.

Our work is important enough to deserve your support here and at home. We are the specialists who work directly with the mentally disabled as a person. To improve our working conditions improves their living conditions. We are tired of emergencies, injuries, mandatory overtime, janitorial duties, and a lack of respect from the medical profession.

And I plead with you here to help us.

Mr. Chairman, I have also prepared a written statement regarding this matter, and ask that it be made a permanent part of this record.

Senator Weicker. Your statement in its entirety will be included in the record.

Mr. Vandagriff. I would like to thank you for this opportunity to speak.

[The prepared statement of Mr. Vandagriff follows:]

ORAL TESTIMONY - APRIL 3, 1985
United States Senate Subcommittee on the Handicapped
Appropriations Subcommittee on Labor-HHS-Education and Related Agencies

CALIFORNIA'S MENTAL HEALTH SYSTEM
Lyle R. Vandagriff, Psychiatric Technician

I. INADEQUATE STAFFING

The patients found in Metropolitan State Hospital are psychotic and unpredictable. Delusional beliefs of fear, persecution, grandeur, and religiosity reach fanatic levels. They see and react to things and people not really there, hear voices which give orders they cannot resist and suffer relentless hallucination. At onset, these patients are consumed with denial, attempting to control their impulses. Eventually, from lack of a believable feedback, they lose contact with reality.

These psychiatric conditions, whatever the cause, create management problems which are at once dangerous, expensive and otherwise criminal. Profit making proprietary establishments cannot afford the liabilities of these patients in the community setting. Patients with such mental disability are frequently physically run down and carry every disease imaginable into the state hospital. They abuse cigarettes, coffee, alcohol, street drugs and medication. They are destructive to property, a danger to themselves and to others.

The kind of patient in the state hospital improves most from the structured routine, often in spite of patient's rights advocates and laws which expect patients to improve from therapy they are allowed to refuse. When patients do get better and are placed in the community, they decompensate exercising their rights and return to the state hospital, caught in an endless cycle referred to as the 'revolving door'.

Recent cut-backs have reduced the quality of life for these patients. Considerably less money is available for outings and recreation. Staffing has been reduced to bare minimums. The fewest licensed staff are now the most we have on duty. The State of California, in preparing schedules, plans to be short staffed. The code of ethics which comes with the license requires Psychiatric Technicians to remain on duty until properly relieved. In this way, if no relief is available, staff who have worked a full shift are required to remain on duty even if they must leave children at home unattended.

To add insult to injury, Psychiatric Technicians, highly skilled in interpersonal relationships and basic psychiatric and behavioral principles, are ordered to work as janitors and housekeepers. So frequently are these duties assigned, it is now expected of the Psychiatric Technician under the auspices of a healthy environment. The groups they once held as therapeutic activities have been displaced by sanitation duties and administrative documentation.

II. HIGH INJURY RATE

The patient's right to refuse treatment, the unpredictable nature of their mental condition, and the lack of Psychiatric Technicians combine to create emergency conditions.

Patients injure other patients much more than they injure staff. Of course, the patient's right to confidentiality prevent the release of information, but in January this year, 59 patient injuries were reported compared to 22 employee injuries (approximately 3 to 1).

The industrial injury statistics show a normal amount of standard industrial type injuries. The addition of patient related injuries at such high numbers and the degree of injury when battered explains the excessive costs for Worker Compensation and Industrial Disability Leave at Metropolitan State Hospital. These employee injuries have cost taxpayers over two million dollars every year, and at a three to one patient injury rate, six million more dollars for care of the patient's injuries, if not more. It would be cheaper to put more Psychiatric Technicians on the floor with the patients.

The behavior of these patients, were it not for their mental condition, would generally be considered criminal when they attack other patients and staff. Unless the patient or staff becomes maimed or loses a limb, the attack is only considered a misdemeanor. These charges are dropped by the District Attorney. If the patient attacks a Hospital Police Officer, however, this crime is a felony and criminal charges are brought against the patient which moves the patient to a more secure environment, a jail, but only temporarily. After the preliminary hearing, the patient is returned to Metropolitan State Hospital. This has proved inadequate to protect Psychiatric Technicans.

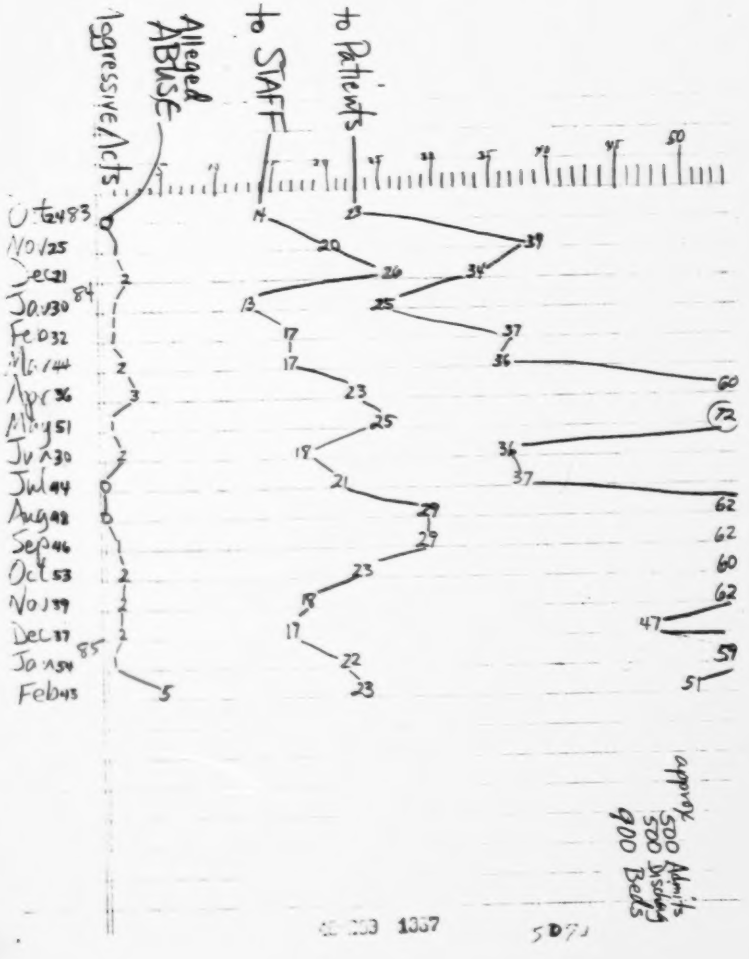
Working under conditions such as these is made worse by disciplinary management. Due to such short staffing, employees are unable to schedule compensatory time off, earned for working holidays. When Psychiatric Technicians use more sick leave than the quota of 16 hours per quarter, they are counselled, merit salary increases are denied as well as transfers and promotions. The requirements of the job are clearly more than a person can do, particularly when the patients are resistive and refusing treatment. Emergency conditions at minimum staffing levels leaves the employee vulnerable to supervisor's claims that they have left work undone. Burnout and stress, with such high injury rates, generates a condition very similar to "battle fatigue".

III. COMMUNICATION PROBLEMS

The patients at Metropolitan State Hospital come from every walk of life. Many are bussed in from other states by families who cannot afford to care for them. Many are drawn by the lure of Hollywood, the mild climate, dreams of jobs, or just hoping to blend in. Many have heard of riches in California's welfare system. Los Angeles has an international cross-section who suffer from culture shock trying to successfully adapt to the American urban and suburban life-style. None are equipped to compete in the free market for jobs, housing, medical care, or food. Not only can language be a barrier to communication, but also cultural experiences.

The Psychiatric Technician is aware of these cultural aspects as they pertain to growth and development, identity, and behavior. The Psychiatric Technician learns to relate to the patient, to explore experiences in search of common ground upon which to build understanding, and if none are found, to create the experiences necessary for communication to take place. Understanding the statements of psychiatric patients can be very difficult. Doctors and other clinical staff have trouble conducting examinations and tests when they cannot communicate with the patient. When clinical staff have difficulty speaking the language of the patient, communication can break down completely. Since so many of the doctors at Metropolitan State Hospital have difficulty with english, they must rely on Psychiatric Technicians to explain treatment to the patient. Some of the doctors cannot practice anywhere else until they become certified in basic english. I don't think this rudimentary skill is adequate to practice psychiatric medicine.

Professional stratification based on the medical model has displaced the Psychiatric Technician trained in a behavioral model. The legal language which provides funds to asist and care for the mentally disabled has excluded the Psychiatric Technician and replaced us with Registered Nurses. There are few of us and we don't have a powerful lobby like the doctors. Our work is important enough to deserve your support here and at home. We are the specialists who work directly with the mentally disabled as a person. To improve our working conditions improves their living conditions. We are tired of emergencies, injuries, mandatory overtime, janitorial duties, and a lack of respect from the medical profession. Help us.



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Communications
Workers of America
AFL-CIO

455 Capitol Mall, Suite 205
Sacramento, California 95814
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March 25, 1985

TO: W. C. DEMERS, VICE PRESIDENT

FROM: CHARLIE STRONG, CWA REPRESENTATIVE

RE: LYLE VANDAGRIFF TESTIMONY

There are several technical errors in the written testimony titled "Employee Abuse in California's Mental Health System". I spoke to Lyle about these but he stated that both this document and one titled "Oral Testimony" have already been submitted to committee staff. The corrections should be made to the staff or the committee by some process. The errors include:

Page 1, Paragraph 1, last sentence, the Superior Court does not lack jurisdiction over state agencies.

Page 1, Paragraph 2, first sentence, the United States Supreme Court in 1969 ruled in "League of Cities" that the Fair Labor Standards Act's application to state employees was a violation of the 10th Amendment, however, in a recent case (Feb. 1985) the court overturned this decision and FLSA has been ruled to apply.

Page 1, Paragraph 2, third sentence, CAL/OSHA is a division of the Department of Industrial Relations, not a Department, also it does have jurisdiction.

Page 2, Paragraph 3, has several errors, the "salary savings" concept was not instituted under Gov. Pat Brown Sr., but rather under Gov. Ronald Reagan, the system and the percentage is controlled by the Department of Finance and changes from budget year to budget year, the filling of vacancies may be delayed until earned holiday and vacation credits are exhausted but compensatory overtime and sick leave do not normally impact, the "merit principle" is in the State Constitution but affirmative action is not.

Page 5, Paragraph 3, second sentence, attacks against Psychiatric Technicians, as attacks against citizens, are either a misdemeanor or a felony depending on the circumstances of the attack, Hospital Police are "Peace Officers" under California law and do have special protections. However, the D.A. usually drops charges in a Peace Officer attack as well because a conviction is difficult, if not impossible.

In regard to the subject matter, much of the testimony relates to matters solely within the control of the State (not the Federal) Government. "Mandatory Overtime" and sick leave administration are problems everywhere but are bargaining subjects and employee/employer relations issues. The entire budgeting process including allocation of staff, budget change proposals, salary savings, hiring of consultants, clearly is under the total control of the State.

Promotions, the "merit system" and affirmative action issues are also clearly not matters of Federal concern except as they may violate civil rights.

Of concern to the committee and the Federal Government are those areas where the Federal Government provides funding. These areas include: staffing levels (the 1:8 ratio), the remodeling of the hospital, and quality of patient care. The state can (if they choose) forego the Federal funding by not complying with the Federal laws and regulations. In fact, the State has in the past done exactly that. The current administration is trying to comply with Federal standards in order to get the money. This is one of the reasons for some of the things Lyle is complaining about.

Current Federal regulations require the "medical model" of health care. This model places the doctor in charge, requires that registered nurses supervise patient care, and fails to recognize the Psychiatric Technician as anything other than an "aide" in spite of their licensed status. One major problem is that the Federal Government "contracts" with the State Department of Health Services to interpret and enforce the Federal regulations. This seems to work well when that Department is monitoring private institutions, but when applying the regulations to State institutions, the Department is mindful of cost and other "special problems" of their sister departments. Being under the executive branch, they are not immune to political pressure. (The current Deputy Director for Hospital Operations in the Department of Developmental Services, [mentally retarded] was previously the head of the Licensing and Certifications Branch of Health Services, the branch which oversees the Federal regulations.)

In his Conclusion (Page 5), Lyle asks for changes in the law to provide sanctions against violent patients (a state responsibility) and more money at the direct staff to patient area (also a state determination). He also, correctly, asks for "legislated status for Psychiatric Technicians". It would also be good to ask that the Feds themselves enforce their regulations with the State Hospitals, rather than the current "fox watching the chicken house" approach.

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Senator WEICKER. Thank you for your testimony. Senator Kerry.

Senator KERRY. Thank you very much, Mr. Chairman.

Mr. Baker, I have read and listened to your testimony, your eloquent statement, with interest, and as I go through each of the numbered problems that you cite with respect to the institutional setting, No. 12 somehow leaps out at me most strongly as the final powerful problem, being this unimportant, irrelevant, nonexistent feeling that people cast on the whole problem as a whole.

Do you accept the notion, in the context of the other 11 problems that you cite, that we are going to have to have some kind of institutionalization; is that correct? There is going to be some level of institutionalized within each State?

Mr. BAKER. One might ultimately draw that conclusion. I think to start with that is starting at the wrong point. I think we have far more institutions than are currently needed, numbers of people in the institutions who should be in the community. At Syracuse well over 200 people—if we had the community option, 450 people live there—well over 200 have been decertified and are supposed to move out and the State gets Federal dollars.

So I would prefer to start on the side of a much larger community options and choices, a more coherent system, and then make the decision on what we need in terms of institutions.

We might end up having to have in some communities small places, very small places. But we have gone berserk in terms of the numbers of places and the numbers of people in them.

Senator Kerry I think that Mr. Vandagriff has accurately described—though I would have some questions about some parts of his testimony—that he has accurately described how some people respond so as to mandate some form of 24-hour care, isn't that correct?

Mr. BAKER. Some people may have to leave their residence for some short period of time—and I would emphasize the short period of time.

But, remember, my testimony was primarily focusing in terms of the needs of retarded individuals, and, as I said before, retarded individuals who go into those places never leave, many of them. There are people on my team who have been in institutions for 70 and 80 and 90 years—some of them have never been out of the building.

Senator KERRY. Now, each of those other 11 problems that you cite, specifically something like basic human needs are not met in an institutional setting, or you look at something like officers and professionals, sometimes consumers, unconscious about the dysfunctionality, or even the problem of rivalry, power plays, struggles—I mean, so much of what you talk about is really a function of the staffing, of the leadership fundamentally; isn't it?

Mr. BAKER. Well, I think perhaps some of it can be laid to leadership. I think the bulk of what I tried to describe in my testimony—one can predict will happen in what I call all congregated settings; the bigger the setting is and the more people you have there, the more numbers of staff and the greater number of people being served, rubbing elbows, sets up a social circumstance where these kinds of things occur. There is no way that the director of the Syracuse Developmental Center, for example, can stop all these power plays.

So what I am referring to is the situation of putting 450 people who have multiply and severely impaired in 1 building, and then putting with that 450 people another 800 staff in various levels—that includes carpenters and security officers and all kinds of maintenance people, nurses and on and on and on.

People lose sight of why they are there and what the major mission is in terms of what everybody should be addressing themselves to. And I think you can go into any large institution and see this stuff going on.

Senator KERRY. Any other large kind of institution or any institution that——

Mr. BAKER. I have worked in psychiatric centers and I saw that going on there, I worked at the St. Lawrence State Hospital and I saw it going on there; I worked in a nursing home in Syracuse and saw it going on there.

Senator KERRY. Is there something that you think, after your experience, that is inherent in the care of people who either have the problem of mental retardation or some other physical impairment—is there something inherent in that kind of care that after a period of time takes its toll on intelligent and sensitive people, or what? I mean, what is it that you think creates this institutional——

Mr. BAKER. Well, the environment is dysfunctional. When you get a large number of people together and try to meet very intricate human needs, it's very, very difficult to pull that off. I do not think that the problem rests in the elderly, it does not rest in the mentally ill, in my estimation, and it does not rest in the mentally retarded. I believe the problem is a social problem that brings about and legitimizes the construction of these huge places where we have got large, large numbers of people, all of whom are separated from society.

I think that is what causes it.

Senator KERRY. What is it that makes you feel, then, that people who are untrained, people who are frightened, people who live with their own fears on a day-to-day basis, and all the other problems that people have, are suddenly going to be better equipped without staffing, without equipment, without training and many other things, when you get it in a much more decentralized form to be able to deal with this kind of problem?

Mr. BAKER. Well, I do not suggest that we take resource, either material resource or human resource, away from the handicapped. What I do suggest is that we disperse, and your question is a good one in the sense that any time you disperse services, it does stress your communication processes and there are a number of coordination kind of things that have to be built into that kind of a system.

But, after saying that, I must hasten to say that the more integrative the service is, the easier it is going to be to get the service and deliver it in a humane way.

Senator KERRY. Did you trace the deinstitutionalization process at all in those States that have tried to——

Mr. BAKER. I am very close to it in Syracuse, very, very close to it.

Senator **Kerry**. Has it been your experience, as it has been ours—we really had to stop; we suddenly said, wait a minute, we are not prepared to do this, and we can't continue, because as people were going into the communities, the communities really weren't dealing with it, and suddenly people who had at least an institutional environment that was trying to care for them were winding up wandering the streets, adding to the list of homeless in the country, and more often than not finding their way into a courtroom where the courtroom was totally ill-equipped to be able to deal with them, and they are ultimately going to jail.

Mr. **Baker**. Well, there are many people in New York State——

Senator **Kerry**. Do you disagree with that having in fact been the pattern?

Mr. **Baker**. I think that is an accurate representation of what has happened.

Senator **Kerry**. If that's true, then, you know, it's sort of a Hobson's choice here, isn't there?

Mr. **Baker**. Well, I think we have got two problems. I think we have certainly got a problem in terms of the way that the deinstitutionalization process has been implemented. In New York State many of the people who were living in institutions end up on the streets and become street people, and experience overwhelming dehumanization.

But the amazing thing that I run into—and I had this experience just within the last month, with two severely impaired people who were living in their own residence in Syracuse—in spite of their deprivation and in spite of their squalor, they did not want to go back to the institution. And there is a tremendous amount of inhumanity wherever you look. We can find it in our community services; we can find it in the institution—the institution abounds with it.

I think the bottom line is what is the model that we are going to subscribe to in this society that probably, given the right kind of safeguards and the right kind of structure and the right kind of coherency, is going to yield the best services.

And my stand on that has to lean on the side of the community services.

So one can—I do not mean by my testimony to convey that community services have been a relative success; they certainly have not. There is a great deal to be done there.

And I think when one looks at that, at the horrors of institutions—and I believe institutions are not going to be made better; I think we need as a society to choose the community direction, and we need to do that wisely and we need to be very disciplined in the way we organize the community services.

And another thing that I mentioned in my testimony that needs to be done—there needs to be in human service, and there needs to be I think a social support for this, there needs to be a commitment to the normalization principle and its implementation.

Senator **Kerry**. Thank you, Mr. Baker. The chairman has informed me—I know we have another panel and we have some folks who want to speak after that. So I will try to be very quick.

I just want to ask you, Mr. Vandagriff, just one quick question, if I can.

You have defended psychiatric technicians, and appropriately so, I think, within the context of your testimony, but I wonder how you respond to what has been said here in these past 2 days about examples and significant ones of large scale abuses over a period of time—and you cited your own form of abuse that technicians themselves suffer in this environment. And you said in your testimony that you are really being asked to do a job that can't be done.

Mr. VANDAGRIFF. That's correct.

Senator KERRY. Well, if you can't do it, who can? And how do you respond to what you have heard here in the last few days?

Mr. VANDAGRIFF. It's not that it can't be done. Given the material and the resources that we have to work with, it's impossible to do it. It's impossible for one person—let me explain the situation that I work in right now. As I said, there are 28 beds on my unit, 27 patients, we have three staff. One of those staff is the supervisor, the shift lead, myself; another person is in the medication room; and that leaves myself and another staff to work with 27 patients. Now, 3 hours out of the 8, one person of those three is on a break, so 3 out of the 8 hours—lunch break—so 3 out of the 8 hours there is really only 2 people to work with 27 patients—and I work in an acute psychiatric unit.

Now, to hold groups and to assist these disturbed patients through those things that you and I take for granted as far as living goes—personal cleanliness and hygiene—to assist them through a routine is very difficult; it's tantamount to a close-order drill; it's not very personal. We are also supposed to document extensively our interactions with the patient.

Well, if the phone rings, someone has to go answer it. Then you add to the difficulties of carrying out a routine to meet the patients' needs, those patients who refuse to participate in a treatment plan; they always require staff attention. If they become violent, if they are upset, or frustrated—they take somebody away from the treatment program to deal with those more immediate emergency type problems.

If we had sufficient staff—we are all trained to do the job; I am very capable of——

Senator KERRY. I read your statement in a different context—and I think it appeared in the testimony in a context that I understood it——

Mr. VANDAGRIFF. Let me get back to the context that I think you meant then.

Senator KERRY. No, I accept that.

Mr. VANDAGRIFF. I can't be responsible for the patient's problems; I can try to help the patient through those problems. But if they refuse to put on socks after I have asked them kindly—we are not very well entitled to restrain them for not wearing socks, and yet I am responsible. That is the situation we find ourselves in.

Senator KERRY. Let me just ask you the second part of the question, then, and we'll close on that: what is your reaction to the instances of abuse that you have heard of a widespread nature across the country?

Mr. VANDAGRIFF. It saddens me in my heart; it's terrible, nothing short of an atrocity that the public needs to become aware of. It needs further investigation before you decide the cause for those people who happen to find themselves working there. My personal opinion is that those people began that career, that work, to help, as a helping profession, and perhaps over years of working in those conditions, the burnout and stress takes its toll, not just psychologically, but also physically. I see very few of my peers surviving the ward environment to make it through retirement. Most of us, through an accumulation of percentages of disabilities over the years, find ourselves thrown away by the system, where we lose our career and are sent home never able to work for the State, county, city, or any other facility because of our injuries.

Senator **Kerry**. Thank you, Mr. Vandagriff. Thank you, Mr. Chairman.

Senator **Weicker**. I think there are some very good points being made here. No. 1, what Mr. Vandagriff just alluded to, in terms of the abuse and the injury that takes place to the staff. This is something that both Mr. Baker and Mr. Vandagriff know of, and the figures are very high in that area also.

You have indicated, I think, in your testimony that people who go into this aren't a sadistic uncaring bunch. I think it's very clear that they are—it's like any other profession—very caring. Many things contribute to the end result. As Mr. Baker says—I don't know where you end up, with the system as it is, as far as institutions are concerned, compared to the community setting.

I think I know firsthand how much attention has to be paid to the burnout problem—and we are talking to you, two of you taking care of 28 patients. Things that we take for granted, they can't do, whether it's dressing or toileting or anything else like that, so it isn't a question of your just taking care of their special needs. You've got to take care of all their routine needs in addition to whatever therapy they might require.

I don't want these hearings in any way to have a finger turned around on persons who work in our institutions. And when I talked to the press the other day, I indicated the matters I have under consideration. One of them is coming at this personnel problem, both in terms of training and in terms of time off, so that we get around this burnout problem. I don't see how you do it. I don't see how anybody under the circumstances you describe—and I will probably get into trouble with all your State directors and budgeting agencies and all the rest—I don't see how you do this thing more than 3 months straight at a crack. You ought to have 3 months off and then come back at it again. I just don't see how you do it.

Mr. **Baker**. Senator Weicker, might I comment to that? On my team at the Syracuse Developmental Center, as I said before, I serve 100 handicapped people, and the emphasis upon my team is to provide services for the 100 handicapped individuals, many of whom are quite severely multiple impaired in the community.

And the first point I wanted to make is that in terms of staff morale, I think if you look at staff morale, delivering services, whether their base of operation is in the institution or whether they permanently work in the community, that staff by and large have much higher morale when they work in the community than when they work in the institution.

Senator **Weicker**. I believe that. Again, I repeat, I subscribe to the de-institutionalization concept. I also agree with what was alluded to by Senator Kerry: you are probably going to have a minimal situation where certain institutions are still going to be there. But I also agree with you: let's not start off on that basis, try to get away from it as best we can.

Mr. **Baker**. We at least ought to stop the construction, and New York State is busily putting brick and mortar together all over the place, and using Medicaid dollars to do it.

Mr. **Vandagriff**. Mr. Chairman, I'd like to tell you that our attrition rate at Metropolitan State Hospital is 30 percent per year. It's true, most of us aren't able to stay there. Those who are able to cope with it only do so as a result of extreme dedication and hardship.

Senator **Weicker**. I don't know if anybody would care to comment. I realize it's difficult to do—but, as much as I condemn it, I can also see how it happens, as has been alluded to by many of the witnesses before the committee: that with cases of staff abuse—I will cut right to the heart of it—comes an exercise in covering your backside, if you will; the staff is not going to lend itself to testimony on reported abuse. Indeed, staff that does tends to jeopardize itself with other staff. I don't know how you get out of that circle.

I know you are not going to condone it, but I have just had too much testimony here from all sides which indicates that it is very, very hard to get staff to step up to bat and report what's going on for fear of jobs, for fear of their fellow employees, et cetera.

Does anybody want to comment on that?

You don't have to. I think the fact is you have had plenty of courage in coming here to testify. I will give you an opportunity to comment on a point that has been raised very prominently in these hearings.

Mr. **Baker**. In institutional settings, I think that often staff are put in untenable situations. Another point I would want to make is that if the service system is structured properly and built upon humane values, handicapped people are a joy to work with. My two handicapped sons are both involved in integrated work settings, and their employers tell me that they enjoy working with them. And I know my staff at the Syracuse Developmental Center, many, many of my staff enjoy working with handicapped people when they have the right kind of support systems. When staff are put in untenable positions with very few staff and many, many demands being made upon them, and a lot of authority thrust upon them, with no support, it's very, very difficult. I think there are very many courageous souls, however, who work on a day-to-day basis with handicapped people who stand and who stand upright in the face of the inhumanity. And I think the people who have testified before your committee, Senator, represent that in this Nation.

Mr. **Vandagriff**. I, too, would like to respond to that. The negligence of the system too often points the finger at the worker who has the least amount of control. I can't deny that there are all of these situations of abuse, but I would like also to point out that it is not infrequent for psychiatric patients to allege abuse or for families to recognize abuse in a system and then, searching for someone to blame, they find the person closest to the problem. Many of the instances of abuse that I have seen reported weren't a particular employee's behavior; rather the resources and the materials and what they had to work with was inadequate for the job—not their personal negligence, but the negligence of the system that turns its back on the problem.

Senator **Weicker**. Gentlemen, I thank you both very much for your testimony, appearing here before the committee. I think it's very difficult in terms of your positions.

I might add I expect to be back in touch with you, because the matter of those who work in the field is one of the areas that we are going to be addressing this year.

You will be of some assistance. I don't see how we can meet the problems that have been presented to us unless we also understand the problems of those who are supposed to do the caring job for all of us—and that is the attendants. For everybody who gets angered by a story of somebody who's gone bad in your profession, might I add that I have been dealing with the whole damn society, some 250 million strong, most of whom, I am sorry to say, don't give a damn, and just are shoving the problem off behind the wall, or handing it to you fellows to resolve.

So, believe me, it's everybody's problem, not just that of a few.

Mr. **Baker**. Thank you for your national leadership on this, Senator.

Mr. **Vandagriff**. I look forward to any opportunity to work with you further.

Senator **Weicker**. Thank you very much.

We will just break for 3 minutes, and then we will move to our next panel.

[Brief recess.]

Senator **Weicker**. All right, the committee will come to order—and we have got to move along here now. We have got some very valuable testimony coming up. I understand Michael has some sort of a bus or train or plane or whatever to catch, and I want to make sure he has the opportunity to do that.

So our first witness will be Mr. Michael Kennedy of the Center on Human Policy, Syracuse, NY.

Michael, good to have you with us.

STATEMENTS OF MICHAEL KENNEDY, THE CENTER ON HUMAN POLICY, SYRACUSE UNIVERSITY, SYRACUSE, NY; STEVE SCHWARTZ, ESQ., DIRECTOR OF THE OFFICE OF PUBLIC REPRESENTATION, STATE OF MASSACHUSETTS, NORTHAMPTON, MA; DAVID SINE, SAFETY OFFICER, NEW ENGLAND HEALTH CARE EMPLOYEES UNION, NEW HAVEN, CT

Mr. **Kennedy**. Thank you.

Senator **Weicker**. I might add that all statements will be included in the record in their entirety, so please proceed in a way that is comfortable to you; we want to hear your whole story, but you don't have to read the statements in their entirety. Indeed, I think it's more interesting—you are all well-experienced and well-versed, and I have a feeling you wouldn't even need a piece of paper in front of you to tell us your feelings on this matter.

You go right ahead.

Mr. **Kennedy**. My name is Michael J. Kennedy. I am 24 years old, and I have cerebral palsy. I lived with my family in Tupper Lake, NY, until I was 5 years old; when I turned 5, I had to leave home because my family could not afford to pay for all my medical needs. From there I moved to an institution in New York City called West Haverstraw, where I lived for 3½ years. From there I moved to Rome State School Institution, where I lived for 8 years. From there I lived at Syracuse Developmental Center Institution where I lived for 4 years. During these 15 years of living in three State institutions, I have experienced a number of abuses. And, if I may add, I only picked three categories for my testimony, but I will be more than happy to answer any other questions that are not on my testimony.

The first one is verbal abuse. The staff would come in every day and use harsh language, and tell us things like "Get in there and clean up that mess, and if you don't get in there and pick up that mess, you are going to get it." Or they would often threaten you with things like "If you don't get in there and pick up that mess, you are not going to eat."

And the second one is drug abuse. One day one of my friends that lived on the unit with me was having a real rough day, and he really needed to talk to someone, and instead of the staff member taking time to sit down and talk with him and find out what the problem is, he proceeded to go get some thorazene. Therefore my friend was out of it for the rest of the day.

And this happened not only to one person, it happened to everybody.

I learned to fear the staff, because I did not know what they were going to do to me or anybody that was with me next.

Today I live in a Medicaid-funded apartment with three other disabled people. It is my home, not an institution. I have my own freedom, I have my own things in my room, I don't have to lock them up. We learned things like doing our own transportation, cooking, laundering, and budgeting money.

After I moved into my apartment, I got a job working with the Center on Human Policy as a self-advocacy coordinator. We have a self-advocacy group that meets once a week, and we are learning things like rights and responsibilities.

I made a lot of progress in my life, but I have a lot of time that I have to make up for. An institution is not a place where anyone should live. They say we had rights, but we didn't; they say we had freedom, but we didn't. I had no say in anything I wanted to do.

And the third thing I notice I've jumped over was minimal schooling. When I was 13 years old I was put into a classroom with 10 other people. I was much more advanced than they were, and they were teaching us things like counting numbers and our ABC's, and that was stuff I had already known. They didn't teach you basic stuff like adding, subtracting, multiplying, and dividing, or everyday skills that you would need to live within the community.

And I would just like to say—I would like to thank everybody for giving me the opportunity to share these experiences, and I am open to any questions that are on my testimony.

Thank you.

Senator WEICKER. Michael, nobody spoke so clearly and so distinctly. Of all the witnesses we have had, you are by far and away the best—no if's, and's, or but's about it. I hear you, I see you, and I hope everybody else does also in terms of what is possible, and the hope that I think you give to many, both by the work that you are doing and by virtue of your own example, is something that is inspiring to everybody in this room.

I want to read one paragraph of Michael's statement that he didn't speak out on.

> When I was 12, I received a model airplane from my father. I loved it and put it together immediately, but every time I put it together, one of the residents would tear it down. I was really mad, so I told a staff member to make him stop and if he didn't that I would hit him. Just a few minutes after that, the resident began tearing my model down again. The staff member just sat there and watched him do it. I was really angry, so I hit the resident, knocking him out of his wheelchair. The staff member came in, got some rope out of the closet, tied it around my feet, and hung me upside down in the doorway.

Mr. KENNEDY. And, believe me, that didn't happen only to me; it happened to every person within that institution. That's why I think they were fearing the staff, because they didn't know what they were going to do next.

Senator WEICKER. If you don't mind me using the expression, Michael—I don't know how many times they hung you upside down, but you certainly landed on your feet.

Mr. KENNEDY. Thank you.

Senator WEICKER. And I think that is testimony to your courage, not to the system.

Mr. KENNEDY. And I would say, too—and this has nothing to do with the testimony, this is just the way I feel in general—I always told everybody that when I got out, things were going to change for the disabled, because there's no reason they should be treated like that; they should be treated just like everyone else.

And I told them that I would do everything in my power to see that that happened.

Senator WEICKER. Michael, thank you for your testimony. Do you have a bus or plane you are trying to catch? I think we had better help Michael to leave—and I really thank you for your testimony.

[The prepared statement of Mr. Kennedy follows:]

STATEMENT OF MICHAEL KENNEDY SUBMITTED TO U.S. SENATE SUBCOMMITTEE ON THE HANDICAPPED

APRIL 3, 1985

My name is Michael J. Kennedy. I am 24 years old. I was born with cerebral palsy and spasticity of my muscles. I lived with my family in Tupper Lake, N.Y. until I was 5, but then I moved to West Haverstraw institution in New York City. I had to leave home because my parents couldn't afford to pay for all my medical needs. Plus, they were both working so they could not give me all the assistance and care that I needed. They also had 3 other children who needed to be cared for. I lived in W. Haverstraw for 3½ years. After that I moved to Rome State School institution and lived there for 8 years. Then I moved to Syracuse Developmental Center institution, where I lived for 4 more years. In the fifteen years I lived in these 3 institutions, I experienced a lot of physical, mental and verbal abuse. I would like to share with you what institutions are like.

Physical Abuse

When I was 12, I received a model airplane from my father. I loved it and put it together immediately, but everytime I put it together, one of the residents would tear it down. I was really mad, so I told a staff member to make him stop and if he didn't that I would hit him. Just a few minutes after that, the resident began tearing my model down again. The staff member just sat there and watched him do it! I was really angry, so I hit the resident, knocking him out of his wheelchair. The staff member came in, got some rope out of the closet, tied it around my feet, and hung me, upside down on the doorway. After about 15 minutes, my father came in to visit, and I was taken down. I probably would have been there a much longer time if my father had not walked in.

Verbal Abuse

Everyday the staff used harsh, obscene language. They would swear at us constantly. For example, a staff person would often scream, "Get in there and clean up that mess! If you don't, you're gonnat get it." I was also threatened with things like, "If you don't do it you are not gonna eat!" I learned to fear the staff. I never knew what to expect from them or what they were going to do to me.

Drug Abuse

One day one of the residents on my unit was having a hard day and wanted to talk to someone about it. Instead of taking the time to talk to him, the staff member gave his some thorazene. He was out of it for the rest of the day.

Not Home-like

The furniture was plastic and uncomfortable. It had a bad odor, too. The colors were ugly. The curtins were made of an orange and yellow pattern, and often one was longer than the other.

On my unit at Rome there were 52 people. There were no beds. We slept in big cribs. Everyone stayed in bed all day except for me. Sometimes there would be only 2 staff people on the unit.

There were no plants. There was nothing on the walls. There was no carpeting. The bathrooms were filthy. Dirty laundry was on the floor. There were big blotches of dirt in every corner. The windows were sometimes so dirty, that you could barely see out.

No Privacy

Everyone went to the bathroom in groups. Often there were no private stalls in the bathrooms. We took group showers, too. The staff used the same towel and washcloth for the whole group, usually about 5 people.

There was no door on my bedroom. About 20 people slept in my room. It was impossible to be alone.

No Personal Relationships Allowed

One time I invited a friend to come to visit me. I hadn't seen her for about 3 months so I wanted to talk to her privately to see how things were going. I started to lead her into my room when a staff member stopped me and began yelling at me. She told me never to "try and do that again". I asked her why. We argued. When my friend left, the staff member smacked me really hard across the head for arguing with her. My head hurt for some time after that.

No Freedom

All my decisions were made for me. I was told when to get up in the morning, when and what to eat, who I must live with and when I must go to bed. It didn't matter whether or not I was tired or hungry. I had to do whatever they said. Very rarely was I allowed to leave the grounds of the institution and never on a spur of the moment decision.

They told us we had rights, but we didn't. They told us we had freedom, but we didn't. I had no say about anything I did in my life.

Dehumanization

Staff members didn't call you by your name. They didn't bother to learn your name. In order to identify you, they would write your name on your back with either a paint brush or a laundry marker. When they needed to know who you were, they would lift up the back of your shirt. When staff members knew you were going home, they would wash the name off your back. (One time they forgot when I went home to visit my family. My mother was helping me get ready for bed when she noticed the paint. She was furious.)

Minimal Schooling

I was put in a class with 10 other people. I was much more advanced than any of the other students. When I was 13, they were teaching me kindergarden activities such as the alphabet, counting numbers and learning shapes. I already knew everything they were teaching me. They didn't teach me things that I needed to be learning like adding, subtracting, multiplying and dividing. The few books that I read were "Dick and Jane" type stories.

Also, they didn't teach any practical, everyday skillslike cooking, cleaning, street-crossing, budgeting money, etc. I had no say in what I wanted to learn.

Depersonalization

All personal laundry was thrown together and washed in bulk. When it was finished it often got lost. I never got all my own clothes back. Instead, I got other people's clothes. One time, I had gotten some new clothes from my family for Christmas. I wore them once, threw them in the laundry and never saw them again.

Personal Belongings Stolen and Damaged

When I was 15, I bought a stereo with money I had saved. A half hour after I had it all set up, a resident came into my room, picked it up, and smashed it all over the floor. When I went out and asked a staff member that the resident pay for the ruined stereo, she said, "No, that won't be allowed."

One Christmas, I received a pair of walkie-talkies from a friend. I opened them up and put them on a nightstand. I left the room for a short time, and when I returned, one of them had been stolen. This incident taught me that all personal belongings had to be kept under lock and key. I could not trust anyone.

Conclusion

Today I live in a medicaid-funded supportive apartment. I live with three other people. It's my home, not an institution. I have more freedom. I have my own things in my room, I don't have to lock them up. I have learned many skills that I didn't have the chance to learn in an institution, for example, arranging my own transportation, some budgeting, and doing my own laundry.

I have a job at Syracuse University's Center on Human Policy as a self-advocacy coordinator. I teach other disabled people to speak out for their rights. I've made a lot of progress in my life, but I know I have a long way to go. I've got a lot of time to make up for. I want to help other people get out of institutions. They're not a place where anyone should live.

Senator **Weicker**. So many of our perceptions are visual. I want to know how many people—not a lot of them in this room, because they are professional—but I want to know how many people on the street, just to look at Michael, would ever believe that he could come and speak and think, such as we heard here today. That's part of the problem right there. He's got as much upstairs and has as much courage and ability to express as anybody, any of us.

But I bet a lot of people, to look at Michael, have condemned him to something a lot less than what it is that he can actually accomplish.

In any event, the next testimony is by Mr. Steven Schwartz, attorney and director of the Office of Public Representation in Northampton, MA.

Mr. Schwartz, nice to have you here with us.

Mr. **Schwartz**. Thank you, Senator, and let me say at the outset that I really appreciate your taking the opportunity to allow people like Mr. Kennedy to testify, because if it wasn't for him and people like him, none of us would be doing the work that we are doing, and people like him really give inspiration and meaning to our lives, let alone our work.

For the past 13 years, Senator, I have represented the residents of the Northampton State Hospital, which is a large custodial institution in Massachusetts. I have been lead counsel in a number of class action and individual cases which were brought to enforce and protect the rights of people confined in State facilities.

Most importantly, during this entire period, I have witnessed, felt, and personally experienced what's done to people, many of them my friends, people with mental illness in State institutions.

Since I know you have already heard a litany of personal tragedies, I will not recount all of the experiences that are set forth in my written testimony. I would like to highlight just a few.

I represented recently an incontinent person, an elderly woman, who was placed under warm water, then drenched with disinfectant, because that was a convenient bathing technique used at the State hospital. I am currently representing a physically handicapped brain-damaged young woman who was carelessly dropped in a bathtub of scalding water and had to spend the next 2 weeks at an intensive care unit in a burn center in Springfield, MA.

These situations, where people are regularly abused, constantly mistreated, consistently drugged—at the Northampton State Hospital, approximately 92 percent of the people are on psychotrophic medication and little else. People are arbitrarily denied their freedom, forced to live in unsafe conditions, and systematically deprived of the fundamental legal rights that our State legislators and Congressmen here in Washington work so hard to enact.

But mostly, Senator, what happens to people in institutions is that they are wantonly neglected. Let me tell you of one of my friends, David, who is a 32-year-old man, black man, from Springfield. He was originally involuntarily admitted to Northampton when he was 16 years old. Eight years later an advocate from my office discovered David, rocking on his bed, mumbling unintelligibly. During those 8 years David was never allowed out of the locked cubicle in which he lived, which was only 120 feet long by 100 feet wide. When David came to the hospital, when he was 16, he could read, he could write, he could converse quite freely; by then, when we found him, he only mumbled. He used to play basketball and worked as an apprentice carpenter in Springfield. When we found him, his physical mobility was markedly impaired. He used to walk freely throughout his neighborhood and take buses in downtown Springfield and go shopping. Eight years later he was terrified of crossing the threshold of his locked cubicle.

At a court hearing, at which I represented him in 1975, involving the question of whether David had to be locked up for yet another year in that hospital, even his clinician admitted that his protracted period of institutionalization had caused him severe harm and he had socially regressed.

Despite this documented history of a century—and it is now almost a century that we are sitting in—of institutional tragedies, there are some persons who may come before you and still advise you that these massive State hospitals can some day provide decent quality care. I wish that they could. They would suggest that if the buildings are simply renovated, the staffing is dramatically increased, that standards such as JCAH or Medicaid were applied to those hospitals and enforced, all would be well. But these illusions of reform are not only contradicted by history—this past century—but they are belied by our present experience even in Massachusetts.

For in Massachusetts, we tend to think of ourselves there as an enlightened State where mental health and retardation care has progressed.

In 1970 we tried all of those solutions to bring together, and we built a brandnew State hospital in Bridgewater, and then the Commonwealth of Massachusetts contracted with the McLean's Hospital, a private facility operated by the Harvard Medical School, to provide medical and psychiatric care through physicians trained by the Harvard School. Today, just today, that institution, which was built for 300 people, now confines over 500 under conditions that are so awful and so appalling that a private Boston law firm had to go into Federal court and challenge unconstitutional confinement there.

Constructing new buildings and increasing staff, even with competent professionals, has made no difference to us in Massachusetts. In fact, the situation has probably worsened. It should now be abundantly clear that State hospitals, as presently constituted, are not only the inhumane environments spoken before, but they are the irreparable product of well-motivated but ill-conceived approaches to caring for people with mental illness.

Let me also share with you something about the people in our State hospitals. Ten years ago, after what Senator Kerry was briefly speaking of as a period of deinstitutionalization in Massachusetts, we had 1,200 residents at Northampton. Approximately 1,000 of those individuals were people who had been confined for years, many for decades. Two hundred of them were also retarded, 100 were children, and 200 more were elderly people.

In 1978, it took a Federal court in Massachusetts to compel the Commonwealth to create adequate community mental health services for former and current residents of that hospital. As a result of these effective treatment alternatives, which have been set up in the last 5 years in Massachusetts, the number of admissions to our hospital has been reduced by 60 percent.

In addition, the hospital population itself now stands at about 185 instead of 1,200, with an additional 100 people moving to less restrictive new community homes in the next year. We have no more children at our hospital. There is only one person with retardation, and he will be leaving by this September. There will only be seven elderly people by that time who have been there for more than a few years. In other words, there will be less than 15 long-term residents at the Northampton State Hospital within a year from now, and virtually this entire long-term population is now living in small community settings in our local neighborhoods in western Massachusetts.

The court order that I mentioned has had a dramatic consequence for David, of whom I spoke earlier. He now lives in his own apartment in a 24-hour-staffed program; he communicates easily; he is playing basketball now; he walks freely to the city of Springfield and goes shopping. And last night I just learned in a telephone call from someone in his program that David will be registering in our local community college next fall.

Thus the most compelling solution to the tragic consequences of abuse and neglect in State hospitals, I would suggest, is the development of community alternatives, well planned, well staffed, considerately developed and humanely operated.

There is an emerging professional consensus that these programs are the most appropriate, and probably the only, alternative to the abuse that you have heard so much about in these last few days. There is now documented experience that they work. However, there is very little Federal financial support for implementing this consensus, and in fact there are concrete physical disincentives, such as the Medicaid program which operates to support many of our federally subsidized State institutions.

Based upon this professional consensus, the National Association for Rights Protection and Advocacy, of which I am secretary, and of which many of its members have testified before you in the last 3 days, will soon attempt to combine its legal, consumer, administrative, and programmatic expertise, because we have people from all of those areas, to try and close one institution in a small State that only has one facility, in order to clearly demonstrate that States can and will be able to adequately serve people in small community settings without reliance on large institutions.

I would just like to close with a few specific recommendations which are outlined more in detail in my testimony.

First, I believe the Federal Government should—it must—encourage State initiatives in developing community alternatives. One strategy for doing this is by expanding the community services waiver under the Medicaid Program of the Social Security Act.

Second, the Congress should reenact section 501(1)(L) of the Mental Health Systems Act, which was repealed in 1981, but which had required recipients of Federal funding to have in place a meaningful client grievance procedure, so at least some of the abuses don't have to be shuttled under the rug, and at least some clients, like Mr. Kennedy, will be able to complain, at least in writing, about being hanged upside down.

Third, Congress should also require that all facilities which receive Federal funds, mental health and mental retardation, ensure that there is an individualized written treatment plan, which is at least the very beginning of being able to provide adequate care.

And, fourth, and what I consider probably most important, Congress has already perceived the importance of federally supported protection and advocacy programs for persons with developmental disabilities. In 1980, it thought of the same thing with respect to people labelled mentally ill, and then promptly repealed that statute in the Omnibus Reconciliation Act. And I think reinstituting some form of protection and advocacy system is essential.

I would like to thank you, Senator, and the subcommittee, for drawing national attention to the plight of citizens who are confined right now in our State mental institutions. I would hope, in fact I would urge you, to take immediate steps to ensure that we don't subject another generation of people with disabilities to lifelong institutionalization.

And I would specifically ask that this committee, through your leadership, take some specific steps to write or sponsor in any way legislation that would facilitate the development of some real community opportunities for people so they don't have to spend yet another generation, and your successor and mine, on sitting before us another 20 years from now. We need your help, Senator—we have no place else to turn.

Thank you.

[The prepared statement of Mr. Schwartz follows:]

CENTER FOR PUBLIC REPRESENTATION

Mental Patients Advocacy Project

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413/584-1644 Ext 285

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April 4, 1985

Honorable Lowell P. Weicker, Jr.
303 Hart Senate Office Building
Washington, DC 20510

Dear Senator Weicker:

Thank you again for the opportunity to present the views and experiences of my clients to the Sub Committee on the Handicapped. The three days of testimony has significantly increased public awareness of what institutionalized people must endure. Hopefully, this will be the beginning of some new possibilities.

I am enclosing a corrected copy of my testimony for inclusion in the full record. I am also available to work with your staff in drafting some legislative remedies to these problems. Your staff might also want to contact Leslie Scallet of Policy Resources, Inc. and Joe Manes of the Mental Health Law Project. Both are dedicated advocates who are strongly supportive of your efforts. They have extensive experience in legislative proposals, are in regular contact with key mental health and retardation organizations, and were instrumental in the passage of the Mental Health Systems Act.

There can be no doubt that your leadership and compassion on these issues is invaluable to people with disabilities who are confined to public institutions. I look forward to assisting you and your staff in any way possible.

Sincerely,

Steven J. Schwartz
Attorney

SJS/MEK
cc: Joyce Lanzerotte
Enclosure

TESTIMONY OF STEVEN J. SCHWARTZ
TO THE SUBCOMMITTEE ON THE HANDICAPPED
SENATE COMMITTEE ON LABOR AND RESOURCES

April 3, 1985

I. INTRODUCTION

My name is Steven J. Schwartz. I am an attorney and the director of the Center for Public Representation in Northampton, Massachusetts. I am also the chairperson of the Massachusetts Coalition for the Legal Rights of the Disabled, the co-chair of the Mental Disability Section of the National Legal Aid and Defenders Association, and the secretary of the National Association for Rights Protection and Advocacy (NARPA). I recently was appointed to sit on the Select Committee on Mental Health Service Delivery Systems, a national planning and advisory commission established pursuant to a grant from the Robert Wood Johnson Foundation to the National Mental Health Association.

For the past thirteen years I have represented the residents of the Northampton State Hospital, a large custodial institution in Massachusetts. I have been lead counsel in a number of individual and class action cases brought to establish and enforce the rights of people confined in state mental institutions. For much of that time I also directed a federal demonstration grant from the National Institute of Mental Health which developed a model for institutional legal advocacy. Most importantly, during this entire period I have witnessed, felt, and personally experienced what is done to people with mental illness in state hospitals and state schools.

II. THE REALITIES OF INSTITUTIONS -- LIFE IN THE NORTHAMPTON STATE HOSPITAL

For those of us working within the confines of state institutions, the legal needs of persons who are labelled as and confined for being mentally ill are an everpresent reality. No formal report or special study need be conducted to document the compelling instances of abuse and neglect of institutionalized persons. Each day that we leave the relative openness of our office at the Hospital and walk onto the locked and barren wards -- which for many of our clients have been their only home for as long as thirty or forty years -- the compelling need for reform, in order to guarantee these citizens their constitutional and statutory rights, is manifestly clear. I would like to tell you of some of what I have observed at the Northampton State Hospital. These observations are not designed to sensationalize but rather to be a simple recounting of what has happened to my clients in that institution.[1]

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[1] A copy of yet another in a series of articles on institutional abuse in Massachusetts is attached as Appendix A.

People are regularly abused. Several years ago I represented an incontinent, elderly woman who was placed under warm water and then drenched with disinfectant as a convenient bathing technique. I am currently representing a physically handicapped, brain damaged, young woman who was carelessly dropped in a bathtub of scalding water and had to spend the next two weeks at an intensive care unit in a burn center. Even more frequently, residents are verbally abused, screamed at, and taunted for everything from failing to get out of bed to demanding an extra cigarette over and above the quota of a few per day.

People are constantly mistreated. The absence of even minimally adequate medical care at Northampton means people with serious physical problems such as pulmonary conditions or phlebitus may go entirely untreated and often die in the state hospital without as much as seeing a licensed physician. One woman developed atrophied muscles in her hand and spent months waiting for promised physical therapy that never materialized. A moderately retarded man was transferred from a nearby state school twelve years ago and, as a result of the absence of any mental retardation professionals, has not received as much as an hour of appropriate programming for over a decade.

People are wantonly neglected. For example, Mr. B. is a 32 year old black man born and raised in

Springfield, Massachusetts. He was originally involuntarily admitted to the Hospital when he was sixteen years old, after a relatively innocuous incident on a bus. A juvenile court questioned his competency to stand trial and, because it did not realize that he was mildly retarded, sent him to the Northampton State Hospital for twenty days of observation. Eight years later an advocate discovered Mr. B. rocking on his bed, mumbling unintelligibly.

During those past eight years, Mr. B. was never allowed out his locked cubicle, which is only 120 feet long by 100 feet wide. When Mr. B. came to the Hospital he could read, write, and converse quite freely; by then he only mumbled. He used to play basketball and worked as an apprentice carpenter; by then his physical mobility was markedly impaired. He used to walk freely throughout his neighborhood and take buses to downtown Springfield; eight years later he was terrified of crossing the threshold of his locked cubicle. At a court hearing involving the question of whether Mr. B. needed to remain involuntarily confined for yet another year, even the Hospital clinician admitted that during his protracted history of institutionalization Mr. B. had been severely harmed and had socially regressed.

People are consistently drugged. A study of the type of treatment utilized at Northampton several years ago indicated that 92% of the residents received psychotropic medication and little, if any, other active treatment. Almost 50% were forced to take several major drugs simultaneously. Just a few months ago a woman had to be rushed to a nearby emergency room after plunging into toxic shock as a result of the overprescription and inadequate monitoring of these drugs. And despite a state supreme court decision over a year ago which required informed consent by, or judicial approval for, persons receiving psychotropic medication, the Massachusetts Department of Mental Health estimates that approximately 60% of the people in their state hospitals are being drugged without such consent.

People are arbitrarily denied freedom. All Northampton residents live on locked wards. Some spend massive amounts of their waking hours in seclusion. Last month at another state inpatient facility, a woman died of an ectopic pregnancy while in seclusion. She was never once examined by a physician at the facility before or during her two days in the seclusion room. The Massachusetts legislature has been so appalled at the way institutionalized persons are frequently restrained and secluded that it established a special investigatory commission to review this practice at all hospitals. As a result, it recently passed yet another law to further restrict the use of these techniques.

Moreover, in addition to locks, Northampton, like all state hospitals, uses that pernicious system called "privileges" to arbitrarily grant or deny residents the freedom even to go to the canteen for coffee, to have a cigarette, or to attend a religious service on Sunday. The system operates without any procedural safeguards, thereby giving staff unbridled discretion to arbitrarily limit a person's liberty -- or even to totally restrict their freedom of movement. This "privilege" system converts fundamental rights into tokens that must be earned by being good and will be withdrawn for contravening some unwritten rule or unspoken expectation.

People are forced to live in unsafe conditions. Northampton, like many state institutions, was constructed nearly a century ago and looks like it. After ten years of complaints, the Commonwealth finally decided to remove the asbestos from the wards at Northampton where 80% of the residents are confined. Three years ago the Department of Health and Human Services decertified Northampton from participating in the Medicaid program because of numerous violations of the life safety code. It then proceeded to decertify four other mental health facilities in the state. Estimates for achieving compliance with safety and environmental standards of JCAH or Medicaid at all state hospitals in Massachusetts runs into the hundreds of millions of dollars.

People are systematically deprived of fundamental legal rights. Despite a plethora of constitutional, statutory and regulatory rights, there are customary patterns of illegal actions by staff at virtually every institution. In Northampton, the regular presence of independent advocates has created a sensitivity to the basic proposition that people with mental illness have legal rights and that the violation of such rights will result in sanctions. But in most state facilities in Massachusetts, a virtual atmosphere of lawlessness prevails. Residents have no privacy; they must search vainly for a staffperson to accompany them to make a telephone call to a family member or clergyman because the pay phone is on the other side of the locked door. They are not given the same access to their medical records, which often contains highly subjective, seriously damaging, and frequently inaccurate information, that a high school student is given to his academic file.

III. THE ILLUSIONS OF REFORM - SOME FALSE SOLUTIONS

Despite the documented history of a century of institutional tragedies, there are some persons who may still advise you that massive state hospitals can someday provide decent, quality care. They would suggest that if buildings are simply renovated, if staffing is dramatically increased, and if accreditation standards such as JCAH or Medicaid were consistently enforced, all would be well. But these illusions of reform are not only contradicted by history, they are belied by present experience. Moreover, they ignore the astronomical cost implications and the reluctance of state and federal legislators to support such a major investment.

In Massachusetts, we have tried all three approaches and they have proved to be false solutions. For instance, the Commonwealth built an entirely new institution -- the Bridgewater State Hospital -- in 1970 to house 331 residents. It then contracted with the McLeans Hospital, a well known private facility affiliated with Harvard Medical School, to provide psychiatric and medical services. Today that facility confines over 500 people under conditions which are so awful that a federal suit was brought by a large Boston law firm challenging the unconstitutional environment and level of care.

Another suit was filed last month by the United States Justice Department against the Worcester State Hospital, which prides itself on its close affiliation with the University of Massachusetts Medical School and its highly trained and well supervised staff. And two weeks ago a third case was brought by the Boston Bar Association challenging inadequate medical care in all of the Massachusetts state hospitals.

Constructing new buildings and increasing staff -- even with competent professionals -- has made no difference. In fact, the situation in Massachusetts appears to have worsened. It should now be abundently clear that state hospitals are not only inhumane environments but are the irreparable products of well motivated but ill conceived approaches to caring for people with mental illness.

IV. RECOMMENDATIONS FOR CHANGE: SOME REAL SOLUTIONS

Let me also share with you something about the people in state hospitals. Ten years ago there were 1,200 residents at Northampton. Approximately 1,000 of these individuals were institutionalized for years, often for decades. Two hundred were also retarded, another hundred were adolescents, and two hundred more were elders.

In 1978 a federal court ordered that the Commonwealth of Massachusetts create community mental health services for former and current residents of the Hospital. As a result of these effective alternatives, the number of admissions have been reduced by 60%. The Hospital population has decreased to 185 residents, with an additional reduction of 100 people projected over the next year through the creation of new residential programs. There are no adolescents at the Hospital today and there is only one person with retardation. Within a year there will be only seven elderly persons and an additional six to ten other adults who have been confined for as long as a year. In other words there will be less than fifteen long term residents left at Northampton. Thus virtually the entire long term population of the Northampton State Hospital will have been placed in small community settings in real neighborhoods throughout western Massachusetts.

This community system is perhaps the most comprehensive of any in the country. All available information indicates that the services are of high quality, that handicapped people's basic rights are fully respected, and most importantly, that people no longer are being neglected but instead are gradually becoming productive members of our local communities.[2]

That court order has had a dramatic consequence for Mr. B., of whom I spoke earlier. Fortunately, given the presence of advocates at the Northampton State Hospital, the situation for him has changed. When an advocate first approached Mr. B., she soon discovered that with a great deal of patience and care his apparent mumbling could be understood. And when, after several months of concerned listening, she heard Mr. B. say that more than anything else he wanted to leave and go back home to

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[2] A copy of the court order and community plan in Brewster v. Dukakis is attached as Appendix B.

Springfield, the advocate explained to him the legal process for requesting his discharge. Mr. B. then signed a form requesting that the Hospital release him and provide him with appropriate care in a less restrictive alternative. Mr. B. now lives in his own apartment with the help of twenty-four hour staff, communicates easily, plays basketball, walks freely throughout the city of Springfield, goes shopping in downtown stores, and looks forward to a far better and more productive life.

Thus the most compelling solution to the tragic abuse and neglect of people in state hospitals is the creation of community alternatives to these institutions. There is an emerging professional consensus that community programs are the most appropriate - in fact the only - alternative to large, understaffed institutions. There is now documented experience that they work. However, there is little federal financial support for implementing this consensus and, in fact, there are concrete fiscal disincentives as a result of federal support to state institutions under the Medicaid program.

Based upon this professional consensus, the National Association for Rights Protection and Advocacy will soon attempt to combine its legal, consumer, administrative, and programmatic expertise to close one institution in a state that only has one large facility, thereby demonstrating that states can adequately and appropriately serve people with mental disabilities without large institutions.

> Recommendation 1: The federal government should support and encourage state initiatives in developing community alternatives to state institutions. One strategy for assisting states is by expanding the community services waiver under the Medicaid program of the Social Security Act.

Another solution is to create procedures which hold staff at state hospitals more accountable and which check arbitrary decisionmaking. A client grievance procedure is a proven mechanism for forcing administrators to address identified deficiencies, to investigate allegations of abuse and other rights violations, and to begin to respect the views of institutionalized people. It also provides an informal, inexpensive forum for resolving disputes without the need for legal action.

After institutionalized people in Massachusetts had filed a federal lawsuit against the Department of Mental Health, the agency promulgated a fair and efficient complaint procedure that is being closely monitored by advocates and administrators.[3] Not surprisingly, recent data demonstrates that almost fifty percent of the complaints filed have been substantiated and responsive action has been taken.

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[3] A copy of the complaint in that case, McBride v. Okin and the negotiated grievance regulations are attached as Appendices C and D, respectively.

> Recommendation 2: The Congress should reenact Section 501(1)(L) of the Mental Health Systems Act, formally Pub. Law 96-398 (1980), which required recipients of federal funding to have in place an meaningful client grievance procedure. 42 U.S.C. Sec. 9501.

Establishing a clear and fair process for the preparation of individual treatment plans similar to that used in special education under the Education for All Handicapped Persons Act (94-142) is another approach that has proved enormously successful in western Massachusetts. The process has provided a valuable mechanism for assessing an individual's needs, defining appropriate services, and ensuring meaningful participation by persons with mental illness and their families.[4] Individual treatment plans are also required under virtually all accreditation standards such as JCAH and Medicaid, are currently being implemented for people with retardation in certified facilities, and represent one of the core elements of what professionals consider to be minimally adequate treatment.

[4] A copy of the Individual Treatment Plan (ISP) regulations of the Massachusetts Department of Mental Health is attached as Appendix E.

> Recommendation 3: Congress should require all facilities which receive federal funds, either directly or indirectly, to ensure that residents of such facilities are provided with an individualized, written treatment plan. This requirement also was included in the Mental Health Systems Act, Section 501 (1)(B) of Pub. Law 96-398, 42 U.S.C. Sec. 9501, and should be reenacted.

Finally, the development of independent institutional advocacy programs is essential. For a variety of reasons ranging from fear of retribution to enforced passivity , many institutionalized persons are simply not capable of protecting their own rights. At Northampton, without our legal advocacy program there would be virtually no system of community services, no grievance procedure, and no process for preparing treatment plans.[5]

> Recommendation 4: As the Congress perceived the importance of federally supported protection and advocacy systems for persons with developmental disabilities, it should act similarly in behalf of those labeled as mentally

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[5] A copy of an article describing standards for effective advocacy programs is attached as Appendix F.

ill and confined in state hospitals. In fact, it already did so once in the Mental Health Systems Act. Congress should reenact this provision in a form which parallels section 6012 of the Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. Sec. 6001.

V. CONCLUSION

Thank you for the opportunity to speak to you today. I am prepared to work with the Sub Committee in any way so that this country does not perpetuate its history of abandoning people with mental disabilities in lawless institutions. In behalf of my friends and clients in institutions in Massachusetts, we thank you for your interest, your compassion, and your leadership.

Senator **Weicker**. Steve, thank you very much. It would be my hope that certainly one, and hopefully more, legislative suggestions that you have made will come to pass this year—this year.

As soon as these hearings are completed, I have instructed staff that they have 2 weeks to prepare for me legislative options resulting from this hearing. And we are going to get to work on it and we are going to pass it. I am not saying we will pass the whole program this year, but certainly with some of these areas—it is only a matter of fine-tuning legislation; we are not talking about new laws, but just adjustments and some amendments in present laws that we should be able to accomplish.

Thank you very much for your testimony.

Our last witness on the scheduled list is Mr. David Sine from Essex, CT.

Mr. Sine, I believe you are here under subpoena, is that correct? Would you please stand and raise your right hand.

[Mr. Sine duly sworn.]

Senator **Weicker**. Please be seated and proceed with your testimony in any way you deem fit.

Mr. **Sine**. Thank you, Senator, I am both pleased and honored to appear before you today.

Let me begin by stating my belief that the issues of of patient safety and employee safety are virtually inseparable within the institutionalized environment for the mentally disabled. The promotion of a safer environment by health care professionals, hospital administrators, safety directors, legislators, and standards writers should be with the design and identification of programs that will improve the level of safety for both the employee and the patient. When we err in this effort, it is when the safety of one party has been enhanced at the expense or sacrifice of the other. Today I have been asked to speak primarily on the issue of employee safety, which cannot truly be addressed as a separate and distinct issue without also giving consideration to the rights, treatment, and safety of the client or patient.

In Connecticut, health care workers at the State institutions run a 50-percent chance of injury. One out of two health care workers in the State institutions will be injured per year. In 1983 the State paid $7.2 million in work-related compensation payments to health care workers. This represents 43 percent of the total paid for all State employee compensation claims, and 58 percent of the total number of claims. 2,500 mental health and mental retardation workers were injured on the job, and 400 of these injuries required that the employee be out of work for 3 weeks or more. This rate of injury is 3 times that of the State correctional officers and 14 times that of the State police.

The Texas Department of Mental Health and Mental Retardation employs 20 percent of the State work force, yet employees of this department were responsible for 56 percent of the compensation claims. Forty percent of these claims were the result of patient-inflicted injuries.

The State of Virginia indicates that 41 percent of the workers compensation claims for the department of mental health and mental retardation were the result of "patient misbehavior" and that 31 percent of all claims over $1,000 are the result of "attacked by/restraining patient."

To understand more fully the nature of these injuries, it helps to look further at the causes and types of injuries that we are confronting. In Connecticut, in 1983, the State-compensated health care workers who had been struck by patients, assaulted by patients, and injured while attending patients $4.9 million. Again, this is 30 percent of the total amount of compensation paid statewide in that year and 68 percent of the amount of compensation paid to State health care workers.

While these actuarial studies are impressive, they do nothing to convey the level of stress, anxiety, and frustration experienced by staff over this issue. Direct-care staff are exposed daily to situations which are potentially violent, situations over which staff believe that they have little or no control, and situations in which they feel trapped between the need to care for the client, administrative policy, and personal safety.

Some recent examples.

Within the month, a female staff member in a neighboring State was attacked by a patient and struck with a chair repeatedly. The staff member received injuries to her face, head, neck, and back and was hospitalized for 3 weeks. The staff member brought charges against the client and the charges were dismissed by the court. At the time of this attack, this staff member was one of three staff working the evening shift on a 32-bed unit. Four of these thirty-two patients are considered to be active and potentially violent. At the time of the attack, four patients on this unit were in restraint.

A 55-year-old male employee has worked for the State since age 22. He has been assaulted and hospitalized seven times with the most recent attack resulting in his being out of work 6 months. The attack occurred on an admissions unit where the employee was struck with a chair, receiving head injuries and a concussion. This employee intends to retire next year.

A 24-year-old female employee has been transferred to a different unit four times. Each request for transfer has been after having her nose broken by a patient on the ward. She has worked for the State 5 years.

A 50-year-old male employee was attacked by a patient and struck in the head with a fire extinguisher. The employee now has chronic migraines and related vision problems.

A 50-year-old male unit supervisor attempts to stop a fleeing adolescent patient on hospital grounds. The employee is knocked to the ground, breaking his hip. The employee has had corrective surgery three times and is still on the job.

No accounting of injuries and episodes would be complete without at least one mention of rape. While not common, this, too, is a very real part of the environment that the institutional health care worker must face. More typical, though, are the kicks, bites, scratches, punches, and thrown furniture. The most common injuries are the products of this type of client behavior, often occurring while staff are trying to restrain or seclude an already agitated client. The result of all this can be an escalation of the frustration level of the staff which can, in turn, lead to violence directed toward the patient.

Recently, several patient deaths have drawn the attention of the media to the conditions within the State institutions. The reports of patient abuse which reach us through the media are those which are the most dramatic, newsworthy, and salable. Many official and substantiated reports do not come to the attention of the general public. These reports of suspected patient abuse are so great in number that nearly every State now has a patient advocate or special investigator which will follow up on all such charges and allegations. Verbal abuse, denial of rights, physical abuse, wrongful death; all are investigated and if verified, disciplinary action, including criminal charges, will follow.

There are several factors which contribute to the current situation. First, our efforts to deinstitutionalize the facilities by finding community placements for those qualified clients has had a dramatic effect on the facilities. While the number of institutionalized clients has been diminished, the type of client has dramatically shifted. The remaining institutionalized clients are those least equipped to deal with the outside world, those who require the most care, and those who are court commitments. Certainly one factor that would make a placement for a client in the community difficult would be a tendency toward violence or aggression. What we have done, then, in effect, is to distill the patient population, and we are left with the most difficult to care for.

Part of our commitment to deinstitutionalization has also been a definition of the right to treatment. This has resulted in a reduction of medication in lieu of treatment or restraint. The reduction in the levels of medication as part of the treatment has also resulted in a patient population that is more able to, if not more willing to, strike out at staff and other patients when afraid or angry.

Staff training levels have not been adjusted to compensate for these two factors. Staff training in how to recognize and deal with an escalating, potentially violent patient is usually lacking. It is not uncommon to find staff that have had less than 5 hours of inservice training on this topic in 3 years. In defense of administrators, however, the current standards, particularly the mental retardation standards, are vague as to when patient abuse begins and personal safety begins. Acceptable training programs in one State are considered to be unacceptable and in violation of Federal standards in a neighboring State. Training levels and content of training programs vary considerably even within State systems. In general, I find the level of safety within mental health facilities to be superior to safety levels within mental retardation facilities. This is attributable in large part to the quality and consistency of the JCAH standards and survey process which has traditionally placed emphasis on issues such as safety, training, and patient rights within the mental health facilities.

Staffing levels have always been an issue brought forward both by unions and patient advocacy groups. Court-mandated staffing levels have been reached in response to a desired level of care and not a desired level of safety.

Staffing level does have a direct impact on training levels, however. Staff cannot be trained unless there can be coverage and there can be no coverage without adequate numbers of staff. For want of staff, training is neglected; for want of training, staff are injured; the injured staff then go out on compensation, do not report for work, and further reduce the number of available staff.

In closing, let me say that I believe that some of our solutions to this situation lie in a clearer set of standards that: First, recognize employee safety and related training as a patient-care issue; and second, give us a clear direction as to acceptable personal safety techniques and limits.

Additionally, we must recognize the change in the institutionalized patient population and respond to this with realistic staffing levels that make possible specialized training in how to deal with aggressive and assaultive clients.

[The prepared statement of Mr. Sine follows:]

TESTIMONY OF:

DAVID M. SINE
SAFETY SPECIALIST
ESSEX, CONNECTICUT

BEFORE THE
SENATE SUBCOMMITTEE ON THE HANDICAPPED
and
APPROPRIATIONS SUBCOMMITTEE ON LABOR-HHS-
EDUCATION AND RELATED AGENCIES

APRIL 3, 1985

First, let me begin by stating my belief that the issues of patient safety and employee safety are virtually inseparable within the institutionalized environment for the mentally disadvantaged. The promotion of a safer environment by health care professionals, hospital administrators, safety directors, legislators, and standards writers should be with the design and identification of programs that will improve the level of safety for both the employee and the patient. When we err in this effort it is when the safety of one party has been enhanced at the expense or sacrifice of the other. Today I have been asked to speak primarily on the issue of employee safety, which cannot truely be addressed as a separate and distinct issue without also giving consideration to the rights, treatment, and safety of the client or patient.

How safe are our institutions for the mentally disadvantaged? Can we consider working in such an institution as an aide or attendant a risky profession? Has an injury due to violence become so common that it could be considered an occupational risk?

In Connecticut, health care workers at the state institutions run a 50% chance of injury. One out of two health care workers in the state institutions will be injured per year. In 1983 the state paid 7.2 million dollars in work related compensation payments to health care workers. This represents 43% of the total paid for all state employee compensation claims and 58% of the total number of claims. 2500 mental health and mental retardation workers were injured on the job and 400 of these injuries required that the employee be out of work for three weeks or more. This rate of injury is three times that of the state correctional officers and fourteen times that of the state police.

The Texas Department of Mental Health and Mental Retardation employs 20% of the state work force, yet employees of this department were responsible for 56% of the compensation claims. 40% of these claims were the result of patient inflicted injuries.

The State of Virginia indicates that 41% of the workers compensation claims for the Department of Mental Health and Mental Retardation were the result of "patient misbehavior" and that 31% of all claims over $1,000 are the result of "attacked by/restraining patient".

To understand more fully the nature of these injuries, it helps to look further at the causes and types of injuries that we are confronting. In Connecticut, in 1983, the state compensated health care workers who had been struck by patients, assaulted by patients, and injured while attending patients 4.9 million dollars. Again, this is 30% of the total amount of compensation paid statewide in that year and 68% of the amount of compensation paid to state health care workers.

While these actuarial studies are impressive they do nothing to convey the level of stress, anxiety, and frustration experienced by staff over this issue. Direct care staff are exposed daily to situations which are potentially violent, situations over which staff believe that they have little or no control, and situations in which they feel trapped between the need to care for the client, administrative policy, and personal safety.

Some recent examples,...

Within the month, a female staff member in a neighboring state was attacked by a patient and struck with a chair repeatedly. The staff member received injuries to her face, head, neck, and back and was hospitalized for three weeks. The staff member brought charges against the client and the charges were dismissed by the court. At the time of this attack this staff member was one of three staff working the evening shift on a thirty-two bed unit. Four of these thirty-two patients are considered to be active and potentially violent. At the time of the attack, four patients on this unit were in restraint.

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In closing let me say that I believe that our solutions lie in a clearer set of standards that:

1. Recognize employee safety as a patient care issue;
2. Give us clear direction as to acceptable personal safety techniques.

Additionally we must recognize the change in the institutionalized patient population and respond to this with realistic staffing levels and specialized training in how to deal with aggressive/assaultive clients.

QUALITY of WORK LIFE
QWL

New England Health Care Employees Union, District 1199
158 Temple Street, New Haven, CT 06510 787-5046

State of Connecticut
State Office Building, Hartford, CT 06106 566-4669

April 8, 1985

Ms. Terry L. Muilenburg
Senate Committee on Appropriations
SD - 131 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Ms. Muilenburg:

I would like to add to my previous written testimony by describing a training program used in Connecticut which has been successful in reducing patient and employee injury. This particular training program is 21 hours in length and was developed primarily by the staff at Altobello Childrens Hospital which serves an active, psychotic adolescent population.

This training (known as S.A.F.E. Training) places a 60% emphasis on verbal and non-intrusive techniques, stress management, and recognition of an escalating potentially violent patient. 40% of the training is taught by an outside consultant/specialist and focuses on the "hands on" techniques that have department approval for managing an assaultive client. The techniques employed are designed so as to maximize both patient and employee safety.

Since the start of the S.A.F.E. Training Program in the Spring of 1984, there has been a 48% reduction in the use of restraint/seclusion at Altobello. This has of course, also had a marked effect on both employee and patient injury. Staff are, therefore, recognizing and defusing potentially violent situations prior to their eruption and the need for restraint/seclusion. Since the start of the training not a single trained staff person has filed a Worker's Compensation claim for injury due to patient assault.

This training is only one of several programs being piloted in the State institutions in Connecticut. While there can be no one program that will be satisfactory for all facilities these are certain characteristics common to successful programs both within this state and elsewhere. Participation by a central office entity which goes beyond endorsement of a program is a requirement. The establishment of policy, goals, objectives and length of training for a target audience should be considered a minimum level participation. Certainly no program no matter how well intentioned will be successful if central office does not approve the hours of staff time needed for its implementation.

Successful programs have all had clear, concise written protocol. Definitions of terms, do's and dont's, and clear limits must be communicated to staff and placed in written form. This will clarify both patients rights' issues and grievance issues down stream.

The length of training does not seem to be as important as does follow up or refresher courses. Again, there must be committment to a continued effort to provide training and the required and continued follow-up. This may involve as many per year hours as the original presentation. Additionally, successful programs have included some provision for post injury interview or counciling. If an employee is injured by a client there is a tendency for the employee to assume that either he/she failed or the training failed. Not all assaults are preventable and the employee must recognize this. An assault does not invalidate either the employees ability or the training program.

While central office support is vital, local adaptation of an overall training philosophy lends credibility at the staff level. Use of local staff as trainers and knowledge (or recognition) of unique facility needs all build a credible program.

Finally, the most successful programs have all had monitoring of results. This has been done with incident reports, compensation data, and seclusion hours. The data has then been utilized by facility quality assurance directors, safety committees, trainers, and central office to further refine and promote the assaultive client training programs.

I thank you again for the opportunity to participate in the recent hearings and hope to work further with the committee on this issue in the future.

Sincerely,

David M. Sine

David M. Sine

DS/m
cc: file
Steve Snider

Senator **Weicker**. Thank you very much for your testimony. You know, your last comments do very clearly bring forth the changing scene. Clearly, if we are deinstitutionalizing and putting people in community settings, those who are left behind are probably the most difficult to deal with.

I think it's going to require additional training and different techniques and different circumstances.

I again repeat I do not in any way want to indicate that this problem lies with the employees. There are employee problems just as there are Senator problems—that's minimal.

What we are talking about clearly is to try all of us being dedicated to finding a resolution for all these problems.

Thank you for your testimony. I do have a few unscheduled witnesses who have asked to appear, so I am going to have to get on with them. And I thank you very much for your testimony.

I've got, unfortunately, only about 20 minutes left of this hearing before I've got to go to the floor. But our first witness has come a long way, and I want to give him the opportunity to testify. I might add: All statements, all testimony, of any witness now appearing will be included in its entirety in the record.

Our first witness is Dr. Thomas Deiker, the administrator of the New Mexico State Hospital, Las Vegas, NM.

Dr. Deiker, welcome to the committee, and, as I indicated, if you have written testimony, that will certainly be included in the record.

Why don't you proceed now in any way that you deem fit—and it's a pleasure to have you.

STATEMENT OF THOMAS DEIKER, ADMINISTRATOR, NEW MEXICO STATE HOSPITAL, LAS VEGAS, NM

Dr. **Deiker**. Thank you, Senator, I appreciate the opportunity to address you. To say the obvious, we commend the committee in its challenging task; it may be one of the most challenging that has faced even Washington.

My entire motivation and purpose for asking to speak this afternoon is not to challenge any of the testimony we heard today, specifically from New Mexico, my own State, or the individuals who testified. My intention rather is to support it.

If I merely did that, I don't think it would be of value to your time. I believe beyond that I would like to suggest to the committee some extremely simple non-resource-related programmatic monitoring issues that I feel might be of some value in this process.

To say the equally obvious to me, I would like to commend the individuals from New Mexico. Without the media holding us accountable, our employees who have courage to speak for what they believe in, the patients and their family members, we probably wouldn't have the muscle to be here today and to have a possible product to come out of it. I strongly plead the committee that there be a product, because, if there is not, I merely go back to my institution with my same problems.

Senator **Weicker**. Rest assured, there is going to be a product.

Dr. **Deiker**. Excellent. I share the curiosity of Mr. Zdravesky, too, as to whether in this specific case of New Mexico, the intent at reform is genuine. I have obviously made a personal judgment that it is and moved my family across the Nation one more time on that gamble. If it is not—people like me don't have very stable employment records—I will have to seek those places where it will.

I believe it is genuine, and the time's chemistry comes together to allow for real change. My own history, without going into it, suggests to this committee that I have seen extremely dramatic, rapid, positive change in institutional settings, and, regrettably, seen equally dramatic, rapid deterioration of those same situations.

I read your committee report; I think it's right on target on a lot of issues. My own personal background again, without going into it, would suggest that the dramatically insufficient aspects of the funding and monitoring mechanisms we see in terms of accreditation, the Civil Rights of Institutionalized Persons Act, the U.S. Justice Department, the advocacy groups, the P and A forums, all have not been sufficient to guarantee acceptable minimal humane care for clients.

To state a very dramatic case, in one institution I was involved in, in which I did run an institution for a period of time, we had the 7-day front-page largest newspaper in the State exposé of grand jury on unlawful death, involvement of U.S. Justice Department for a period of 2 years, involvement of the American Civil Liberties Union for an equal amount of time, involvement of a civil advocacy group for an equal amount of time. Change was dramatic and change was reversed equally dramatically.

I have told my staff consistently in my career: We are 1 week away from where we started at any point in time in terms of reform.

I would have considerable unease about being in the position I occupy if it wasn't for some very simple things—and, in the case of my current employment, I have told my immediate staff I will have the possibility of being fired either for doing my job or for not doing my job; you will be fired before I am—that's the only way I have to extend that torch down an organizational structure.

New Mexico, frankly, recruited me because I have the reputation of being a reformer. It is an accident and coincident only that I have the only published data on the nature, extent, and severity of institutional abuse, and I think it's of value to the committee that I share it with you.

I share that with you not because it will surprise you, not the data; what I would like to point out is the context in which it takes place. The title of this article is "Institutional Abuse of Developmentally Disabled Clients in a 'Protected' Population." The word "Protected" in that title is in quotes. They were protected by a Federal court with a special master.

This article describes the results of an internal abuse-reporting system for 241 class members of the Gary W. class which were returned to the State of Louisiana following a Federal lawsuit in terms of violations of their civil rights.

One of the mandates of the court order in that suit was that every class member shall be in a setting in which there is a mandated abuse-neglect reporting system, there is an independent phone, there is an aggressive special master—and only those of you who have ever met Dr. Sougant [phonetic] would know what the word "aggressive" means. He is an extremely powerful advocate of patients' rights.

There was external investigation through the child-protection system of the State for any and all allegations; there was referral to law enforcement.

The data: For 241 class members, there were weekly allegations of abuse and neglect; there were confirmed or substantiated abuses every other week. On a statistical basis this says that 8.3 percent of clients are abused, substantiated abuse, on an annual basis. If you had one of your children in that protected class, you would expect multiple instances of institutional abuse in their institutional lifetime.

The physical violence rate alone, narrowing the type of abuse to that, was 50 per 1,000 per year. This is two to three times the reported physical violence experienced by the general public in stratified random-sample surveys of neighborhoods; 82 percent of the abuse was staff-originated; 29 percent of those were terminated. Although there were some referrals to criminal justice system agents, there were no grand juries or no true bills returned.

What is important about that data—and I will be glad to make it available to the committee—is not that it exists, but the context in which it exists. We could spend our entire time here trying to design a circumstance in which we could guarantee the rights of the patients. My point to you is that this was done; an entire class of people was placed under the protection of a Federal court, there was a special master appointed to care for their rights, to investigate randomly their cases. There was a reporting system mandated; there was independent investigation of all reports; there was a 24-hour toll-free number to call to assure nonrecrimination.

In that setting, abuse was two to three times, in terms of physical violence, the expectancy of being a private citizen. Whatever the justification for an institutional system, obviously the last final rationale, after all the other arguments are laid aside, of providing asylum to a helpless client from a cruel world obviously is seriously challenged by data of this type.

Senator **Weicker**. In other words, this data is collected while these children are under the care of the master appointed by the court.

Dr. **Deiker**. Correct.

Senator **Weicker**. I would very much like to have that.

Dr. **Deiker**. OK. This is pending for review at one of the mental retardation journals.

To continue, I would suggest to you, from my own experience, that you and I could write an equation for abuse and neglect, if we backed into this problem and said how could we systematically design a situation in which people would be guaranteed to be abused and neglected. I think we could rather simply do that.

The first requirement is that we stigmatize people. It doesn't make any difference how we do that; it could be the color of their eyes, race, sex, age, marital status. Their disability is an obvious simple way to stigmatize people.

Then we need to congregate them and we need to segregate them from society. That should ideally take place involuntarily.

Then we would probably choose a total-care setting where their entire external needs are provided by external agents under external agents' control.

A controversial issue of this equation that we could debate forever I will simply label and move on. The philosophy by which we do that, I think, is critical. All evil I think comes from an essentially good intention. I think the system of care in our Nation is a paternalistic system; it is one in which we "take care" of people. I would merely label for you that the expression "take care of" has two meanings; one involves breaking kneecaps and the other involves altruism.

If we really wanted to guarantee that abuse would take place, we can go far further. Those direct-care staff workers that have to deal with the difficulties of very difficult clients—ideally, if we wanted abuse, we would make sure that they were untrained, unpaid, unrewarded, uninvolved, unsupervised, unsupported, and unmotivated.

Those equations apply, I would challenge you to consider in an extraordinarily diverse number of circumstances—they are not just the mentally retarded or the mentally ill; that obviously applies to prisons and nursing homes, day treatment centers, community residential settings for the disabled; it applies to military academies, it applies to religious communes. There is a wide variety of circumstances it applies to.

If you or I were to abolish abuse, we obviously, if that is the equation, would have to reverse it—and you heard a lot of dramatic testimony about the kinds of things that would entail.

We obviously would have to destigmatize, integrate, individualize, normalize, and make voluntary the services we provide.

Senator **WEICKER**. Let me say this—this is an imperfect world, we all are human beings. If I could get the statistics vis-a-vis this population down to the same level as applies to the whole population, I would be entirely satisfied. Even there, obviously, abuse, etcetera, is going to take place.

What bothers me is that part of your report where it is, under optimum circumstances, 2 to 3 times what it is in the normal population.

So I don't mean to say that these things don't go on—they will always go on—but to be so disproportionate—it's trying to cut down that disproportion that I am involved in. I wish I could say that we are going to achieve Nirvana here, but we are not, and we know that.

But the alternative is to live with what we've got, and that is unacceptable.

Dr. **DEIKER**. I think, Senator, the view from the inside is that none of us who deal with these problems on a daily basis have much idealism left; we are pragmatists. Our entire focus is like yours, on what can we realistically do to curb the most dramatic of the abuses we expect. We do not intend to reform human nature; we know there will always be violence when humans are involved.

I would suggest to you that there is an antagonism between the needs of an institution—and, if you ran one, you would have that same antagonism. The needs of an institution are simply order, efficiency, and control. The needs of the individual are growth, differentiation, freedom, development.

With limited resources there is a clash in an institutional setting between those two needs.

The solution to this problem, I put to you, is maybe more courage than is commonly found collectively among us. I think it takes taking on a very powerful vested interest. I would simply like to outline the dimensions of that vested interest.

It is not an issue of resources—it is essentially not an issue of resources. The institutional system continues over the last generation of the so-called community-based movement to consume nationally in excess of 70 percent of the budget. There are numerous myths about this process. I would put to you a couple that are extremely well-documented.

One is the myth of deinstitutionalization. The GAO in 1978 did a study very clearly showing that the percent of the general population in institutional settings has not gone down in the last generation. That should signal to you a notion of the strength of the vested interests we are dealing with. It is not an issue of money.

In terms of the mentally ill alone, there has been an 80-percent drop in those confined to psychiatric facilities; that is more than accounted for by transinstitutionalization, meaning movement largely to nursing-home settings.

There has been in the period, the last generation, of a decrease of 80 percent of the daily censuses in mental facilities; there has been a real growth in the absolute funding. Funding has increased, not decreased. In the last decade, where the population has been dropped by 50 percent, there has been a 35-percent noninflationary real growth of budget.

The deinstitutionalization movement, regrettably, is largely a myth.

There is a new myth which is very current that I wish to consult with Congress very seriously to question. The myth is: Now that we have discovered institutions are not consistently humane, therapeutic, or positive, or productive in their enterprises, that at least we need to keep them because they are cheaper. There is a myth that if we really did create community-based services, it would be more expensive.

I have another paper which is in press, on hospital and community psychiatry, I would urge to you, as proof to you that this was equally a myth. The title of that paper is "The Pat Paulson Plan, Formula Funded De-Institutionalization." We took the chronically mentally ill—and anyone with a sixth grade education who has been taught to count, add, subtract, and divide, knows that if I tell you nationally on the average we spend $50,000 in 1985 per patient per year for custodial nontherapeutic institutional care, no one in the world would believe, in the absence of any data, that you couldn't do it cheaper. And that is the humor in the title, "The Pat Paulson Plan."

Senator **Weicker**. Dr. Deiker, I am going to have to ask you to wind up your testimony, because I have a couple more unscheduled witnesses, and I know that this has to close down by 1 o'clock, no later.

Dr. **Deiker**. Then I will simply jump forward in less than 60 seconds to say, those of us in institutions take no offense if you ask us very directly have we stopped abusing our patients today? I can say yes. I think one of the things in the hospital I am in, I would say I am probably the only one in the Nation that can say yes—because we are putting in place that we say Joint Commission, HCFA certification and State licensing needs to do.

The one thing which has not been done, in order to identify and control abuse, is to very simply ask the clients themselves: have you been abused today? We have a five-point corrective action plan at New Mexico State Hospital where we do exit interviews of every discharged patient, asking him very directly: have you been abused today?

All the certification monitoring—and we get a baker's dozen at every institution—we have health officers, fire marshals, grand juries, coroners, licensing, certification, accreditation and professional societies—none of those societies with joint commission accreditation, costing us $20,000 per visit—none of those monitoring procedures bothers to ask the patient: how have you been treated?

We suggest that in addition to the funding incentives for treatment, that this committee address that appalling absence of the simplest way of all to measure and define abuse. Let's ask the patient. In addition to square feet, lumens of candlepower, and fire exits, let's ask the patients whether they are being treated appropriately in monitoring processes.

Thank you.

Senator **Weicker**. Dr. Deiker, thank you very much. Any further testimony will be included in the record. I want to thank you for making the effort to come a long way. I wish you luck in your mission.

And I would hope that within the year that I will hear both from you and from Mr. Zdravesky to see how things are going. I realize there is a change of the guard here, which hopefully will mean a change for the better insofar as the patients are concerned. And I think it would be very unfair to go ahead and go through the litany that I have heard and lay it at your doorstep. I think what's more important is where will you all be at the end of this year.

Thank you very much.

Dr. **Deiker**. Thank you, sir.

[The prepared statement of Dr. Deiker follows:]

SUBMITTED BY

DR. THOMAS REIKER

ADMINISTRATOR, NEW MEXICO STATE HOSPITAL

April 3, 1985

Abstract

The rate of institutional abuse/neglect for 241 class members under court protection, as confirmed by independent investigation, was 8.3 per 100 clients per year. Physical abuse accounted for 60% of the cases, sexual abuse for 14% of the cases. In 82% of the cases the abuser was a staff member of the residential facility; 29% of accused staff were terminated from employment. Given a rate of injury higher than estimates in the general population, and the expectancy of multiple instances of substantiated abuse/neglect per client in a residential career, the role of the institution as an "asylum" is questioned.

Institutional Abuse of Developmentally Disabled Clients in a "Protected" Population

There is essentially no published data on the frequency or severity of abuse/neglect of clients in residential care (Armstrong, 1979; Hanson, 1982; Sundram, 1984). Estimates of client abuse in institutional settings range from "rare" (Edwards & Reid, 1983) to "endemic" (Sundram, 1984). An important moderating variable in such frequency estimates is the narrowness of abuse definition. If operationally defined as that which results in disciplinary action, institutional abuse is rare indeed. In New York's mental health system, disciplinary action was taken in only 10 cases over an eight month period covering 38,000 employees (Sundram, 1984) and 46,000 episodes of patient care (National Institute of Mental Health, 1983). Conversely, if abuse/neglect is defined broadly to include failures to provide appropriate or needed services, it would be a "regular and daily occurence" in public facilities (Sundram, 1984). Similarly, an increasing number of professionals consider institutional systems to be abusive by definition, at least for some populations (Robin, 1982).

Equally important in estimating frequency of institutional abuse is the degree to which reporting of incidents is supported at the facility level. Reporting is more often punished than rewarded (Durkin, 1982), with the result that allegations are infrequent even when mandated by law. The San Francisco Abuse Council, for example, found virtually no reports of institutional child abuse in a six county area over a five year period. When compliance with the reporting law was encouraged, 75 cases were documented in two years (Gil, 1982). Even children will self-report abusive treatment when assured confidentiality and given access to a reporting mechanism such as a telephone (Thomas, 1982).

In the absence of rigorous internal mechanisms, external monitoring systems provide a basis to estimate abuse. On such instance is the Gary W. (1976) case. A right-to-treatment class action suit, Gary W. challenged the adequacy of treatment programs in out-of-state institutions for mentally retarded, physically handicapped, and emotionally disturbed Louisiana children. One of the Court-ordered protections for class members returned to Louisiana institutions is an abuse/neglect monitoring system. The system includes: definitions of reportable incidents; procedures and deadlines for reporting and internal investigations; referral of all allegations to the local Child Protection Unit for independent investigation; a computerized case file of incidents, with semiannual written summaries to the Court and plaintiffs; and active monitoring of compliance by a Court-appointed Special Master. The present article summarizes the first 2.5 years of abuse/neglect allegations under this mandated system.

Results

Subjects were those 241 Gary W. class members in out-of-home placements under Louisiana Department of Health and Human Resources jurisdiction for the period of reporting, 2/1/82-7/31/84. During that time the State was in the process of implementing least-restrictive placements for these clients. However, after two years all but 52 clients remained in institutional settings, usually larger (more than 15 beds) intermediate care facilities for the mentally retarded (ICF/MRs). In the final six months, an additional 72 clients were moved into community placements, so that a total of 124 (52%) were residing in: family or foster care (14 clients), group or community homes (81 clients), or small ICF/MRs (14 clients).

Class members ranged in age from 12 to 30, with a mean age of 22; 74% were males; 57% were black; 95% had a diagnosis of mental retardation.

Of the 154 allegations of abuse/neglect reported over the 2.5 year period, local Child Protection Units determined 53 cases to be "substantiated abuse." Of these, 3 incidents had occurred in the community while the class member was not under the care and supervision of the residential facility. Characteristics of the remaining 50 cases of substantiated institutional abuse were:

The Abuse. The annual rate of substantiated abuse for the 241 clients was 20 per year. The expected rate of substantiated abuse/neglect per client was approximately once per 12.0 years of institutional residence.

Categories of abuse for the substantiated cases were: 1) Physical Abuse = 30 cases (60%), including: spraying with mace, slapping, hitting, beating with a hard object, striking, kicking, lacerating, choking, overturning a wheel chair or throwing to the floor, locking in a room, not feeding, using corporal punishment. 2) Sexual Abuse = 7 cases (14%), including: sexual intercourse, rape, masturbating or being masturbated by a client. 3) Verbal Abuse = 2 cases (4%), both consisting of cursing a client. 4) Neglect = 10 cases (20%), including: medication errors, failures to monitor or supervise with resulting injuries, leaving a client unattended, tying a door shut to a client's room. 5) Other = 2 cases (4%), both consisting of placing a client in a "time-out" room, an activity prohibited by Court order for class members.

The Abused. The 50 cases of abuse/neglect represented 42 clients, with 8 clients experiencing 2 cases of substantiated abuse. Clients with substantiated abuse did not differ significantly from nonabused clients in age, sex, or race.

The Abusers. In 41 cases (82%), the abuser was a staff member of the residential facility. In 6 cases (12%), the abuser was another client. In 3 cases (6%), the abuser was unknown.

A total of 45 staff members were accused of abuse/neglect in the substantiated cases. Following the mandatory internal investigation, administrative actions taken towards these staff were: termination from employment or resignation in lieu of termination = 13 staff (29%); disciplinary action less severe than either termination or suspension (reprimand, counseling, or inservice training) = 10 staff (22%); no disciplinary action or reversal on appeal of disciplinary aciton = 20 staff (44%); and disciplinary action pending = 2 staff (4%).

Discussion

The present data provide the first reported estimate of the rate of institutional abuse for a defined population, based on a uniform method of reporting and verifying allegations. These estimates are conservative from a number of standpoints:

First, there was considerable self-selection against reporting or substantiating "minor" abuse, abuse by other clients, verbal abuse, or neglect. Only 32% of the substantiated cases were of this nature, though in practice they constitute the majority of cases (Spreat & Baker-Potts, 1983).

Second, many more than the 50 "substantiated" cases involved probable client abuse/neglect. An additional 23 cases were labeled "concerned, but unsubstantiated" by the Special Master. The term covered a variety of cases: allegations substantiated by the facilities, but not confirmed by the Child Protection Unit (5 cases); allegations not investigated by the Child Protection Unit (3 cases) or felt to have represented a conflict of interest (1 case); instances in which abusive physical injury was demonstrated, but with insuffcent evidence to verify the source (4 cases); client injuries which were attributed to policy and procedure failures rather than personal malice (7 cases); and inabilities to confirm allegations (3 cases). In an additional 26 cases, client injury was found (redness, scratches, bruises, swelling, cuts, broken or fractured bones), but was determined to have been accidental, self-inflicted, caused by another client, or of unknown origin. As a matter of customary practice, most injuries of undetermined origin in institutions are termed "accidental." The result is an "accidental" death rate in institutions 5.4 times that of the general public (Public Health Service, 1984).

Third, the present rates are those for a "protected" population. Facility administrators and direct care staff were aware of the status of each class member. It was in their vested interest to avoid incidents involving class members, since it brought immediate attention from the court, state administrative offices, and funding sources. The fact that administrators were unable to prevent abuse even for these clients is support for the belief that line staff lie outside institutional control (Sundram, 1984).

The belief that punishment for abuse is a rare event, is also supported. Of the 111 staff alleged to have been responsible for abuse/neglect, only 17 (15%) were removed from employment. And only 13 (29%) of staff accused in substantiated cases were removed. Although criminal charges were filed in some cases, no charges were accepted by local district attorneys. On the other hand, the present data show that cases confirmed by external investigation will result in separation from employment for nearly one third of accused staff, a rate significatnly higher than traditionally believed (Sundram, 1984).

The proportion of physical versus sexual abuse is similar in the present study to Gil's (1982) rates for institutionalized children and youth, with physical abuse occurring at about 3-4 times the rate of sexual abuse. This undoubtedly reflects both greater staff acceptance of aggressive (Krause, 1974) as opposed to sexual (Shore, 1982) interactions with clients, and the fact that staff tend to be assigned to same-sexed clients in institutions.

The rates of substantiated abuse in this protected class should be a matter of concern to both program planners and the public. At the present rate, these clients would each expect multiple abuse episodes in an institutional career. The rate of physical violence experienced by these class members, 50 per 1,000 per year, is higher than estimates of personal violence in the general public, 15-38 per 1,000 per year (Hindelang, Gottfredson, & Garafolo, 1978). This calls into question the final rationale for the traditional custodial institution, that of providing asylum (safety) to clients (Bradley, 1978). The most direct test, of course, is to compare abuse rates for the same clients inside versus outside an institutional setting. That study is now in progress.

References

Armstrong, B. (1979). A question of abuse: Where staff and patient rights collide. *Hospital and Community Psychiatry*, *30*, 348-351.

Bradley, V. J. (1978). *Deinstitutionalization of developmentally disabled persons*. Baltimore: University Park Press.

Durkin, R. (1982). No one will thank you: First thoughts on reporting institutional abuse. In R. Hanson (Ed.), *Institutional abuse of children and youth*. New York: Haworth Press.

Edwards, J. G., & Reid, W. H. (1983). Violence in psychiatric facilities in Europe and the United States. In J. R. Lion and W. H. Reid (Eds.), *Assaults within psychiatric facilities*. New York: Grune and Stratton.

Gary W. et al v. State of Louisiana et al, 437 F. Supp. 1209 (1976).

Gil, E. (1982). Institutional abuse of children in out-of-home care. In R. Hanson (Ed.), *Institutional abuse of children and youth*. New York: Haworth Press.

Hanson, R. (Ed.) (1982). *Institutional abuse of children and youth*. New York: Haworth Press.

Hindelang, M. J., Gottfredson, M. R., & Garofalo, J. (1978). *Victims of personal crime*. Cambridge: Ballinger.

Krause, K. (1974). Authoritarianism, dogmatism, and coercion in child care institutions: A study of staff attitudes. *Child Welfare*, *53*, 23-30.

National Institute of Mental Health (1983). *Mental Health, United States 1983*. DHHS Pub. No. (ADM) 83-1275. Rockville: Author.

Public Health Service (1984). *Vital statistics of the United States, 1979*. *Vol*. *II*. *Mortality*. Hyattsville, MD: National Center for Health Statistics.

Robin, M. (1982). The abuse of status offenders in private hospitals. In R. Hanson (Ed.), *Institutional abuse of children and youth*. New York: Haworth Press.

Shore, D. A. (1982). Sexual abuse and sexual education in child-caring institutions. *Journal of Social Work and Human Sexuality*, *1*, 171-184.

Spreat, S., & Baker-Potts, J. C. (1983). Patterns of injury in institutionalized mentally retarded residents. *Mental Retardation*, *21*, 23-29.

Sundram, C. J. (1984). Obstacles to reducing patient abuse in public institutions. *Hospital and Community Psychiatry*, *35*, 238-243.

Thomas, G. (1982). The responsibility of residential placements for children's rights to development. In R. Hanson (Ed.), *Institutional abuse of children and youth*. New York: Haworth Press.

Senator **Weicker**. Mr. Bruggeman.

STATEMENT OF ROBERT BRUGGEMAN, PARENT

Mr. **Bruggeman**. Senator, I appreciate your giving me this opportunity, and know you well for your fairness in hearing both sides of questions.

And I am not too sure my statement here is apropos to what the hearing is all about. Basically I am not a professional in the field of mental retardation; I am a parent. And many of my fellow parents feel a little bit threatened abcut the terrible stories that we have heard here—not stories, but facts—of the abuse that goes on in institutions.

We have our children in an institution which we like. I searched for 3 or 4 years in seven States looking for a place, and in the Northern Virginia Training Center, I finally resolved that this was a place for my daughter. She is totally incapable of doing anything for herself. She would not fit in a group home of any kind—bathroom facilities and all these things would take a great expense.

So I feel like the Chafee bill that is coming out today—we feel a little threatened that they are trying to do away with institutions. And maybe a lot of them should be. There are only 280 children or people in the training center. My daughter is in a unit where there are 12 people. They go out to the community each day and to schools, workshops, and activity centers; they have been to the Icecapades; they have been to the St. Patrick's Day parade; they are going to the circus; they have therapists, they have doctors immediately available; and they have dietitians, and each one of them has a different diet each day, and each food is prepared separately for them to obtain their best health and condition. It's not perfect—nothing in this world is perfect. And we really would like you to come and see the place some time.

Senator **Weicker**. How old is your daughter, Mr. Bruggeman?

Mr. **Bruggeman**. She's 22 years old; she's been there 2 years, and for the other 20 she was at home. My wife and I have cared for her since the day she was born.

Senator **Weicker**. Let me say this to you, because I have been deeply involved in the matter that you have raised here, those parents who have their children in an institution—and, yes, they in Connecticut feel just as threatened as you feel in the sense of this deinstitutionalization movement.

What is so heart-rending about it is that for many of the children—I don't know the status of your child—the reason why—and they are usually the older children as compared to those, let's say, 10 years of age and younger—the state of the art has changed in terms of education, and so that many of those children enjoy a situation today vis-a-vis their mental and physical abilities that is considerably different from the child born 20 years ago, through no fault of the child, through no fault of the parent.

Everybody that says, well, the Federal Government doesn't do anything right—let's face it, in this area of the special education money that the Federal Government has put out, it has changed the state of the art.

Mr. **Bruggeman**. Greatly.

Senator **Weicker**. And I can only assure you this, and your friends: nobody is going to leave anybody behind—your daughter, you, the mother, your friends in similar circumstances. You have had a hard enough time; I am not about to go ahead and add to that.

This is a delicate act that we are trying to construct here, to make sure that your daughter has every bit as much love and attention and care as she has ever had, and has the greatest possible opportunity. I might add, she's a young girl, she has a lot of life left ahead of her.

And we are not unmindful of the various forces pulling and hauling, I want you to know that.

Mr. **Bruggeman**. Thank you, sir, thank you very much. We feel that the big thing that has happened is that the parents have participated; they are the advocates, they are the outside advocates, they have inside advocates—and they have tremendous community support from corporations, from the electric company, from C&P. We've built a big swimming pool, we've built four or five playgrounds, we have a pavilion for outdoor barbecues, and we have a nature path where the wheelchair people can go out in the trees and this sort of thing.

It's possible with the parents—this is the big thing—if the parents are advocates, and those who aren't fortunate enough to have advocates, that the ARC citizen advocacy program can come in there and make sure that every child, every person, has an advocate to avoid abuse.

Senator **Weicker**. Well, I am glad you came and testified, and the chairman will express for the record that the point of view expressed by Mr. Bruggeman has many advocates, many advocates. In my own State of Connecticut, believe me, large groups feel just as you do, so this wasn't just an isolated point of view that has been expressed here; indeed, it is one of the most difficult situations that we confront.

And you were very kind to come here and testify before us, and we much appreciate your courage in doing so.

Mr. **Bruggeman**. Thank you very much, Senator.

Senator **Weicker**. Is Sue Davies here, director of the Berks County Mental Health Association of Reading, PA?

STATEMENT OF SUE DAVIES, EXECUTIVE DIRECTOR, BERKS COUNTY MENTAL HEALTH ASSOCIATION, PA

Ms. **Davies**. Thank you.

Senator **Weicker**. At 1 o'clock—you know, we have rules around here—probably nobody knows that one of those rules is that by law I cannot have this hearing go past 1 o'clock—so there's our restriction.

Is there anybody else that has something to say? All right, let's let Ms. Davies go—Sue Davies of the Berks County Mental Health Association.

Ms. **Davies**. The problems which I will present regarding local Berks County in Pennsylvania will tragically not be unique. Further, for all of our discussion these 3 days, I am convinced nothing will change unless Senator Weicker gets the support needed to enact those changes in our protection of persons receiving treatment, which he discussed earlier this day.

In all of this, I wish to make this panel and audience aware that our veterans' hospitals may be the worst offenders in virtually every area of humane treatment, rights protection, and advocacy.

I do hope testimony will be aggressively pursued for this most vulnerable group, not deserving of this reward after serving this country to protect the rights of their own abusers.

My original testimony was to share four cases with the panel from the hundreds that we received last year. They included the death of an elderly woman after suffering from a perforated ulcer for 4 days, almost 3 days of which she was totally ignored; the first time ever, medication of a woman appealing her commitment (one of several sabotages of this particular appeal); staff disregard for the emotional trauma of a client who witnessed another client's death from a bus backing over his head, resulting in aggressive acting out and assault charges against the witness/client. This prevented transfer for more adequate treatment; switching a client to a locked ward simply for the purpose of receiving medical assistance benefits, and his subsequent deterioration due to his transfer. Sitting through the testimony of Monday and Tuesday, I have chosen to set these cases aside. I believe their experiences to be no less serious than the many we have heard in these few days, the details of which will not add substantially new concerns or solutions. Instead, I will briefly list the present systems, treatment and advocacy dilemmas which we are faced with each day.

As stated in earlier testimony, inmates of institutions do not enjoy the same access to law enforcement and protection agencies as do other citizens of this Nation. Patient abuse, therefore, becomes a point of negotiation between staff and management rather than a criminal matter. The fact that there is more potential risk than reward in reporting an abuse is horrifically real.

Professional therapeutic staff of our State institutions who come from other lands (one-third of Pennsylvania psychiatrists) should not be allowed to practice without adequate command of the English language. I cannot help but believe the serious language and cultural barriers between clients and professional staff leads to additional likelihood of medication as the primary mode of treatment as well as inappropriate diagnosis and medication.

The behavior-management rather than therapeutic approach to treatment must be eradicated. The parent-child I'm-OK—you-are-not reward-punishment medication-as-primary-mode-of-treatment paternalistic system to which we subject our family and friends undermines all good therapy and we are firmly convinced that no good treatment can occur without respect and dignity for the client.

Program audits, qualification audits, and client self-evaluations of the institutions in which they are incarcerated are already long overdue, as well as an investigation of the effect of Reaganomics on the several support services each client needs to remain in the community.

The horrendous across-the-board cuts in human-services delivery have resulted in increased institutionalization.

This rise in admissions has created increasingly overcrowded and dangerous environments due to the overcrowding itself, staff burnout or inability to give appropriate care, inadequate discharge planning, quick-fix solutions such as overmedication or restraint control, and a critical lack of opportunity to head off client-staff or client-client abuses which may have been averted with appropriate attention at an earlier moment.

We have had clients who have sat in the institution on a first-time commitment for over a month before seeing a psychiatrist or other treatment team member. Many more who simply languish in wards for lack of programming become the targets of impatient staff as they vie for, literally, crumbs of attention.

The Berks County Mental Health Association has no all-encompassing solution to the serious problems we have as a nation with our attitudes concerning citizens experiencing serious psychological difficulties. We strip them of their credibility, of their awareness of themselves, of their most basic civil liberties—and their worth to themselves and others. Yet, we expect them to heal, be the way they were before, or leave the hospital "fixed." Most awesome is our national delusion that this healing can take place in an environment which permits cramped conditions, no privacy, intimidation and arbitrary decisions by persons in power over one's destiny, woefully inadequate professionalism, forced idleness, chronic misdiagnosis and mismedication, language barriers in a therapy of words, victimization of every type found in the worst of city streets—and no viable protection from all that may occur.

Let us hope for great good luck for Senator Weicker in this enormous task. A great deal needs changing, beginning with the protection system which gives our institutionalized citizens the voice and authority they need to be dealt with as human beings throughout the therapeutic process. Good therapy will follow only after these mechanisms have restored human dignity and respect to the client.

Thank you very much.

[The prepared statement of Ms. Davies follows:]

TESTIMONY

SENATE SUBCOMMITTEE ON THE HANDICAPPED

PATIENT CARE, ABUSE IN STATE INSTITUTIONS FOR MENTALLY DISABLED PERSONS

Submitted by:

BERKS COUNTY MENTAL HEALTH ASSOCIATION, Pa.

SUE L. DAVIES, PRESENTOR

April 1, 1985

My name is Sue Davies, and I am the Executive Director of the Berks County Mental Health Association, Pennsylvania. To the best of our knowledge, we are the sponsors of the original, independently staffed External Ombudsman project for the mentally ill in this nation. Established in the community and our catchment area state institution (I do not use the term hospital, deliberately), we have received complaints regarding the myriad of issues addressed over and over during these hearings. However, the primary service institutions of our client population are Wernersville State Hospital, Farview State Hospital, Berks County Prison and Eastern State School and Hospital, as well as our community programs. Statistics include close to 10,000 complaints received, not only locally, but from across this country, and on occasion as far away as Europe and Japan. We have attended over 1,000 involuntary commitment proceedings for the purpose of monitoring such hearings and enhancing the client's ability to present his or her defense. The Berks County Mental Health Association is a client-centered advocacy project, funded primarily through the United Way of Berks County, Pennsylvania. Such funding allows us to be free of some of the dilemmas of internal advocates and other government funded resources, such as Legal Services Corporation. The continuing instability both in funding and mandate of these groups further emphasizes the need for external advocacy programs free from conflict of interest and political concerns.

The problems which I will present regarding local Berks County and Pennsylvania will tragically not be unique. Further, for all of our discussion these three days, I am convinced nothing will change unless Senator Weicker gets the support needed to enact those changes in our protection of persons receiving treatment, which he discussed earlier this day.

In all of this, I wish to make this panel and audience aware that our Veterans Hospitals may be the worst offenders in virtually every area of humane treatment, rights protection and advocacy. I do hope testimony will be aggressively pursued for this most vulnerable group, not deserving of this reward after serving this country to protect the rights of their abusers.

My original testimony was to share four cases with the panel from the hundreds we received last year. They included the death of an elderly woman after suffering from a perforated ulcer for four days, almost three days of which she was totally ignored; the first-time ever, medication of a woman appealing her commitment (one of several sabatoges of this particular appeal); staff disregard for the emotional trauma of a client who witnessed another client's death from a bus backing over his head, resulting in aggressive acting-out and assault charges against the witness/client. This prevented transfer for more adequate treatment; switching client~~s~~ to locked ward~~s~~ simply for the purpose of receiving medical assistance benefits, and his subsequent deterioration due to this transfer. Sitting through the testimony of Monday and Tuesday, I have chosen to set these cases aside. I believe their experiences to be no less serious than the many we have heard in these few days, the details of which will not add substantially new concerns or solutions. Instead, I will briefly list the present systems, treatment and advocacy dilemmas with which we are faced each day.

As stated in earlier testimony, inmates of institutions do not enjoy the same access to law enforcement and protection agencies as do other citizens of this nation. Patient abuse therefore, becomes a point of negotiation between staff and management rather than a criminal matter. The fact that there is more potential risk than reward in reporting an abuse, is horrificly real.

Professional, therapeutic staff of our state institutions who come from other nations (1/3 of Pennsylvania institution psychiatrists) should not be allowed to practice without adequate command of the English language. I cannot help but believe the serious language and cultural barriers between clients and professional staff, leads to additional likelihood of medication as the primary mode of treatment, as well as inappropriate diagnosis and medication.

The behavior management, rather than therapeutic approach to "treatment" must be eradicated. The "parent/child," "I'm OK/you're not," reward/punishment, "medication-as-primary-mode-of-treatment" paternalistic system to which we subject our family and friends undermines all good therapy and we are firmly convinced that no good treatment can occur without respect and dignity of and for the client.

Program audits, qualification audits and client, self-evaluations of the institutions in which they are incarcerated are already long overdue, as well as an investigation of the effect of Reaganomics on the several support services each client needs to remain in the community. The horrendous across-the-board cuts in human services delivery have resulted in increased institutionalization. This rise in admissions has created increasingly over crowded and dangerous environments due to the overcrowding itself, staff burnout or inability to give appropriate care, inadequate discharge planning, quick-fix solutions (overmedication or restraint control), and a critical lack of opportunity to head off client/staff, client/client abuses which may have been averted with appropriate attention at an earlier moment.

We have had clients who have sat in the institution (on a first time commitment!) for over a month before seeing a psychiatrist or other treatment team member. Many more who simply languish in wards for lack of programming, become the targets of impatient staff as they vie for, literally, crumbs of attention.

The Berks County Mental Health Association has no all-encompassing solution to the serious problems we have as a nation, with our attitudes concerning citizens experiencing serious psychological difficulties. We strip them of their credibility, of their awareness of themselves, of their most basic civil liberties--and their worth to themselves and others. Yet we expect them to heal, "be the way they were before" or leave the hospital "fixed." Most awesome, is our national delusion that this healing can take place in an environment which permits cramped conditions, no privacy, intimidation and arbitrary decisions by persons in power over one's destiny, woefully inadequate professionalism, forced idleness, chronic misdiagnosis and mismedication, language barriers in a therapy of words, victimization of every type found in the worst of city streets--and no viable protection from all that may occur.

Let us hope for great luck for Senater Weicker in this enormous task at hand. A great deal needs changing, beginning with a protection system which gives our institutionalized citizens the voice and authority they need to be dealt with as human beings throughout the therapeutic process. Good therapy will follow only after these mechanisms have restored human dignity and respect to the client.

Thank you.

Senator Weicker. Sue, thank you very much. Your statement in its entirety will be included in the record, and I greatly appreciate your being here for days and then only getting a few minutes at the end to testify.

But I am delighted to have your testimony.

Ms. Davies. Thank you.

Senator Weicker. I thank all who have testified. I now only hope that we are up to the task that sits before us.

At this point we will insert into the record statements subsequently supplied to the committee by interested parties.

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APRIL 4, 1985

United States Senate
Sub-Committee on the Handicapped
113 Hart Senate Office
Washington, D.C. 20510

Attention: The Honorable Senator Lowell Weicker

Reference: Testimony To Be Submitted Into
Sub-Committee Hearings

Dear Senator Weicker:

As the daughter of a patient who died at the Clarks Summit State Hospital, in Scranton, Pennsylvania, I can't express to you enough, my deepest and sincerest appreciation for the effort and consideration you have displayed by the work of your Senate Sub-Committee.

What you have established and what you intend to accomplish is of the upmost importance in achieving quality and loving care for the handicapped. We can not allow our society to become a breeding ground for people who thrive on abusing those who are less fortunate and ask for the least out of what life has to offer.

On March 12, 1985, I voluntarily testified at a fact-finding Commission hearing into alleged abuses at the Clarks Summit State Hospital. This hearing was chaired by Senator John E. Peterson, with a panel consisting of Senator Robert J. Mellow, Senator Raphael Musto, and House Representative, Frank A. Serafini. I am know, hereby, submitting that same testimony to be included into your transcripts of the Senate Sub-Committee Hearings. I have been informed by Sue Tarno, of the Mental Health Association in Harrisburg, that you are still accepting testimony.

I am offering to you, as I have to Senator Mellow's Staff, my assistance and availability to offer imput to your most genuine concerns and efforts in helping those people who cannot help themselves and have no one else to help them.

Sincerely,

Cynthia Barbett

Ms. Cynthia Barbett

CB:
Enclosure

P.S. You know, Senator Weicker, the Handicapped are PEOPLE too !!!

CLARKS SUMMIT STATE HOSPITAL

HEARING

MARCH 12, 1985

Testimony of Cynthia Barbett

Residence: 603 Wheeler Avenue
Scranton, Pa. 18510
(717) 342-0338

Reason for Testifying

Testifying on a voluntary basis
into the death of my mother,who
was a patient at the CSSH

I allege that the Clarks Summit State Hospital is solely and entirely responsible for the death of my mother which occured on October 16, 1983. I am accusing this Hospital of negligence and I will in the following, substantiate, to the best of my knowledge, the events and happenings that led to the reckless and uncaring manner that my mother was treated, which in turn led to her death on October 16, 1983.

My Mother, Jennie Barbett, was admitted on June 1, 1983 to Clarks Summit State Hospital by a petition for Involuntary Treatment under Section 304 of Mental Health Procedures Act of 1976. My mother was 61 years of age and has been suffering from depression since late 1980. It had come to a point where my father and myself could not in the best interests of my mother, provide the proper care that she needed. My mother had been hospitalized at the intermediate unit for the Mentally ill at the CMC Hospital on three (3) separate occasions, and also participated in the day programs at the Scranton Counseling Center. Every effort was made to give my mother the best means of psychiatric treatment, even to the point of acquiring one of the best known private psyciatrists, Dr. Guido Boriosi.

When my mother was admitted at the Clarks Summit State Hospital, she was suicidal. My father and I did the best we could to instill in Jennie, the will to live. It nearly tore both my father, and myself apart to put her in that Institution (CSSH). But we were told it was for her protection. What protection? She was there only one month and she fell, which should have never happened. My mother had a right hip prosthesis performed earlier in the year and the Hospital was advised that my mother needed assistance in ambulating. After her fall at the CSSH, she was sent to the Scranton State Hospital and was treated for a left hip fracture. She returned to the Institution approximately six weeks after and was sent to Ward 8. My mother ate very well in this ward, and to the best of my knowledge, she was eating whole foods. In this particular ward, my mother learned to smile, something she had not done for a while. She also related to other patients and was beginning to make progress mentally.

In the beginning of September, Jennie was transferred from Ward 8 to Ward 14 for better access to the physical therapy department. If you ask me, it was for the convenience of the Hospital and not for my Mother's convenience. Ward 14 was known as the "Medical Building". I can't imagine why it was called the "Medical Building". There was very seldom any doctors around. The Staff usually consisted of maybe one RN, and other staff members, including aides. They all have one common complaint - Not enough help, and not enough state funds to acquire the proper help needed. The patients that were in this ward, were geriatric patients. I did not feel that my mother fell into this classification, although everyone on staff treated her as such. They did not want to give my mother the attention that was needed. On several occasions, we would request that my mother, with the permission of the doctor, be given meals that were not ground or pureed like that given to geriatric patients. The medication my mother was on would leave her mouth very dry and coupled with her many anxious moods, she would have a difficult time swallowing her food. We were always told that as long as she was watched and cautioned to eat slow that certain whole or soft foods were permissable in her diet. Dr. Boriosi was aware of this and allowed us to feed her like this all through her illness. We would suggest this to the Hospital staff and they would agree to discuss it with the doctor, but never did. They would act like the dicussions never took place.

We, (my father and I) went through this ordeal, more than once or twice a week. You may think this is petty, but when a person is mentally ill for three (3) years and is reaching out for the need to live again, and all she asks is to have a decent meal; well, I don't think that is to much to ask. THE ONLY ENJOYMENT MY MOTHER HAD WAS SEEING HER GRANDAUGHTER AND ENJOYING A GOOD MEAL. This was expressed many times to the nurses. They ignored us, they did not care. Any physical or emotional factor that can make a mentally ill person show a favorable response should not be left untried, but should be explored. If they had, at least shown some inkling of consideration or cooperation, it wouldn't have been so bad, but they didn't. In my opinion, for my mother's sake, I think she deserved better.

Another example of lack of consideration and total disregard for a human being's dignity, that was shown to patients at this Hospital is the fact that they were not allowed to have a bath more than once in a five day period. I remember I walked in, on more than one occasion, and my mother would have a terrible stench to her. When I would question the staff, they would look at me like I asked them for the moon. There were times when my mother was left sitting in her urine or stool. The same thing happened when my father visited. If it wasn't her urine or stool, it was her food that was splattered all over her. You could tell that she was not properly bathed. When my father questioned the staff, they told him that they could not give a patient a bath more than once in a five-day period, BECAUSE THEY DID NOT HAVE ENOUGH HELP. The only way we got my mother to have a bath more than once in a five day period was to threaten to go to superiors and/or the Department of Health. That was the only way to get support or cooperation. They treated us like intruders - not visitors. This did not help my mother's condition, any more than their lack of cooperation concerning her diet.

My father and I did not realize that an Involuntary Commitment meant a total loss of identity from a patient and their family. We did not realize that an Involuntary Commitment meant a person no longer was treated with respect and dignity. You have to encourage a mentally ill person to have a reason for living. How can you do this without treating a person with dignity or respect. If anything, this Institution takes away a person's dignity or respect.

On September 21, 1983 a very critical and serious action took place at the Clarks Summit Hospital. As I stated previously, the only enjoyment, my mother had while at this Instition was eating. So, one day I brought my mother a sandwich and while I was watching her eat, she started to choke. One nurse who happened to be walking by, and an aide named Joe, came to my mother's assistance. The Heimlich Manuever was performed, but was unsuccessful. My mother was stripped naked, and back thrusts were immediately applied by Joe. She went/into unconsciousness. They told me, when I asked what I could do, to call the other staff members, and to bring an instrument to clear my mother's airway. Approximately one minute passed, when my mother gained consciousness. I thanked them, especially Joe. I don't think my mother's life could have been saved if it wasn't for him. In fact the nurse admitted that she would not have been able to apply the back thrusts as well as Joe did. They reminded me of what could happen if whole food was given to my mother again and the nurse stated that this is why the Hospital cautioned us about bringing her food. If this was so, then why did they let my mother choke approximately three (3) weeks later on pureed scrambled eggs.

The above incident had to be the most terrifying incident of my whole life. I would never have been able to accept the fact that my mother died from food that I had brought to her. We were cautioned about bringing my mother food, but never told not to bring it.

My mother was placed in this Institution for her protection at the request of the State. While being treated at this Hospital, my mother in a four to five month period, has fallen and fractured her hip, was not treated with any dignity by being allowed to sit in her stool, and had her clothes stolen; and finally came to her death. A death that was clearly not warranted by neither her physical nor her mental condition - but only warranted by gross negligence.

On the morning of October 16, 1983, my father received a phone call from Dr. Parsick that my mother had died. If I recall correctly, Dr. Parsick stated to my father that they thought she had choked and asked if we wanted an autopsy performed.

When my father arrived at the Hospital to identify my mother's body, my brother and I accompanied him. My father asked the nurse what happened. The nurse told my father that she was about four (4) feet away from my mother with her back towards her when she heard a noise from where my mother was sitting. The nurse approached my mother but could not get a response. She was brought to her room after losing consiousness, oxygen was given to her, CPR was administered, but no vital signs appeared, because my mother was dead.

On the Friday before my mother had died, My mother's psychiatrist for most of the past three (3) years, Dr. Boriosi told my father and I not to give up hope, that my mother seemed to be getting better and would be transferred back to Ward 8 which would have made my mother very happy. She had friends in Ward 8, patients who liked and missed Jennie. They reacted to one another with a sense of awareness and caring. If that is all these people had left in life then this is what should be preserved for them by this Institution and not taken away.

My Father, my brother, my sisters & I all realized that my mother could possibly remain in the CCSH for the rest of her life. But if it was a comfortable and content life, then we would have been satisfied. She was there to be kept alive by trained professionals that guaranteed that she would not be left alone while eating. There should have been better care given to my mother.

One day, I discussed my mother's care with the nurse who assisted in the choking incident of 9/21/83. She had the nerve to ask me how I would like to put up with this Institution 8 hours a day. No one asked her to work there. Her attitude is only a sample of what some, not all, of the employees at the Clarks Summit State Hospital have.

Signed and Prepared by
Cyntha Barbett

April 2, 1985
APR 5 1985

The Honorable Senator Lowell Weicker, Chairman
Senate Sub-committee for the Handicapped
113 Hart Street
Washington, D.C. 20150

Dear Senator Weicker:

I have read the Star-Telegram this morning giving a resume of the testimony before your committee yesterday, have listened to the early news on TV, and have heard a report of Ted Koppel's program last night. As a parent of a 30 year old son residing at the Fort Worth State School for three and a half years, I should like to add my testimony to that given yesterday.

I feel that Edward, with Down's syndrome, limited speech, and functioning in the range of severe retardation, has freedom on the large campus of the Fort Worth State School that he could never have in a small community-based home. Basketball and swimming are part of his weekly schedule. It is unrealistic to think that students living in small group homes will receive better medical and direct care than those living in a well-run institution. Certainly the question of supervision will be more difficult. All parents will agree that institutions are not perfect, but staff is dedicated to improving service to our sons and daughters. Parents want a long-range plan and a permanent home for our children when we are gone. The isolated homes scattered throughout communities,where they are not wanted,will bring on a new set of problems. Please read the enclosed newspaper story from Irving, Texas which appeared in the Star-Telegram this morning. It sounds as if these young people would have been better off living in an institution.

May I also comment on testimony given to your committee yesterday? The tragedies which occurred to these children at Fort Worth State School are unpardonable. Be that as it may, as a parent I feel that it IS my responsibility to buy Edward's clothes and shoes and constantly monitor his situation. If I felt he were living in a filthy environment, I would not leave him there a second day.

I am convinced that certain attorneys are using this conflict between parents and professionals as a means of fattening their pocketbooks, and that investors are using this opportunity to build group homes to make money just as many did when there was a great rush to build nursing homes some years ago. Many of these people are not interested in solving the problems of the retarded. They are only interested in making money.

Most sincerely,

Lucy Ryan Muse

Mrs. Edward M. Muse

April 1, 1985

Senator Lowell Weicker Jr.
Atten:Tracy Crowley
SH 303 Hart Senate Office Bldg.
Washington, D.C. 20510

Dear Senator Weicker:

Per your letter to me of March 11,1985. Attached is my statement concerning abusive treatment of the handicapped at institutions.

Very truly yours,
Dorothy Miller
Dorothy Miller

Statement of Dorothy Miller

I worked at the Colorado State Hospital (C.S.H.) for sixteen years and one of those years was spent at mental Retardation Center(now known as the Pueblo Regional Center). I was transferred to this area of the institutional campus to receive training and receive my cerftificate in mental retardation training. I witnessed routine slapping of residents and observed one particular incident in which a client was pinned to the floor and forced spread eagle while another employee kicked that client in the crotch repeatedly. The crotch area was specifically designated as these employees claimed " the bruises won't show here." After unsuccessful attempts to report patient abuse at the ward and division levels in 1973 I reported these abuses and the technicians responsible for it to a grand jury that was in town at the time, investigating the Pueblo Police Depart. Technicians Madrid and Armstrong worked directly under the supervision of R.N. Virginia Ruddick (now Cooper) who coincidentally is the current training supervisor at the Pueblo Regional Center. These technicians were shown preferrential treatment and as a result nothing was ever done about my complaints.

Patients were hearded into shower rooms like cattle and any attempts by an employee to provide positive treatment was underminded by non-caring staff members. The lack of proper coverage added to the problem. I often occupanied a patient to the surgical ward for sutures and other medical treatments. I asked the doctors on duty to give the client something for the pain. The response was "they don't need it, they have a high tolerance of pain."

I eventually transferred back to the psychiatric wards at C.S.H. I didn't even bother to pick up my certification for the M.R. training because I felt it was all a farce, since the special programs they taught were unrealistic and impossible to apply.

We have schools and programs that we're subject to, but that doesn't neccessarily mean anyone that completes the training is qualified to work with the mentally ill or retarded population. Qualities such as honesty, sincerity and consistency have to be inborn and cannot be acquired by any program. Honesty by far has been totally overlooked. In this society its difficult for us to accept that disturbed people don't chose to be that way. People are quick to put their values and expectations on another and then wonder what went wrong. Mis-diagnosis is complemented with incorrect treatment and examples of those results follow:

1.) Daniel Montez jumps off a bridge.

2.) Albert Aragon commits suicide.

3.) Barbara Weaver Sullivan shoots herself in the head.

4.) Charles Terrones is released and murders Mrs. Lynch.

5.) Richard Patton is released and presently trying survive in the community even though he is very ill.

6.) Stella Gonzalez complains repeatedly about abuse by staff members. Disregarded.

Another walked off a balcony while on pass killing himself. Many others have died by hanging or shooting themselves. This is in direct connection from exposure to the Colorado State Hospital system.

Throughout my tenure at C.S.H I have worked with some excellent employees. However the Merit Work Performance Plan and Evaluations used to rate an employees performance has lost its true objective since the supervising R.N.'s do the only evaluating. The lack of input allowed by the person being evaluated is unfair since they don't have the option to evaluate the R.N.'s performance.

Working in the psych field can be difficult. The amount of power you have over another person destiny is traumatic. On ward 81 I witnessed direct care staff band together and discredit psychiatrists who wouldn't do as they had suggested. There has been and apparently still is a strong contention for power which ultimately contributes to poor morale because of the infighting that results. During 1981 which would be my last on this unit I was subjected to different types of harrassment by the supervising R.N. Everything form extra duties to being singled out for improper English and penmanship. Mr.Weicker, I was a good therapist and state employee but refused to compromise my integrity. I wanted to turn to the Union but decided to quit when the current president of A.F.S.C.M.E. (Phyllis Zamparripa) informed us "Well guys, bill 305 passed. Now you either kiss your supervisors ass and take them out to lunch or your jobs on the line."

At one particular time during treatment rounds a mental health worker made a statement about a former patient who had returned. "Lets get him out of here, I don't like him." I replied, "What does your personal feelings have to do with his treatment.?" I was setting up medications on a different occasion and another employee Patricia Steel Valdez was to be monitoring a patient who was tied down in the seclusion room. I believe his name was Brandon. They released one of his arms so he could eat at 5:00 p.m. then left him unattended untill they eventually went on dinner break at 6:00 p.m. At this time Security Police arrived and they told them they were getting prepared to excercise the patient. I verified this because I escorted them into the seclusion room and found Brandon in the same position they left him. He could have easily committed suicide in this position. I wrote up the entire incident as factually as it happened. The rest of the staff was not happy with me, to say the least. Two months later I was ushered off the unit.

My last day at work I tried to explain to my peers that they could easily be in the same position I was, in respect to the outcome of their performance evaluations. The R.N.(Delores Gonzalez) replied," I don't think so Dorothy, because your not human!" That R.N. was eventually transferred.

I never really understood all the reasons why I was released from my career untill Nov. 25,1984. On this date I spoke with another employee Kay Naranjo, who stated "Well, Dorothy, our afternoon supervisor, Erlinda Cordova, told them, you said you would kill her!" I was shocked! This was never presented to me and I was not allowed to address the administration or rebut the accusation.

I was unable to draw unemployment and unable to find employment in this field since then. I have excellent reccomendations but that is nullified whenever a perspective employer contacts the ward. I am classified as workable and have been placed 20th on a hiring list. I recently called back and now I'm 35th. I shouldn't have been on the list at all. I was eventually labeled as being"sick" and other employees were told not to confer with me.

Kay Naranjo eventually quit C.S.H. in September of 1984. She has stated that many more patients have died since my release in Feb. of 1982.

In another incident I witnessed patient John Benfatti unjustifiably and maliciously attack a transient patient in front of the nurses station. I documented the entire incident and John eventually would be moved to maximum security. I escorted John to court to stand trial for the incident but it was dismissed. John's parents are prominent people in the community and I ran into them just recently while in the company of Pueblo Chieftain reporter Ron Martinez. Mrs.Benfatti stated "John is worse than ever and apparently was mis-diagnosed from the beginning." She refused to have her circumstances printed in the newspaper.

In summary, I would like to point out that since the ruling,that patients could be placed on Social Security, the most chronically ill have been released immediately. This could show evidence of documented progress with the acutely ill which they dealt with from 3 to 6 months. The chronics were placed on medication and shifted to nursing and boarding homes. You can see many of these same people walking around town helplessly. They lack the sufficient intelligence to interact with the community and even if they could, they are rejected anyhow. These people are still dependent on us but we have failecd to provide the correct rehabilation and follow up measures necessary to guarantee them quality life. They are labeled outcasts and have been stripped of their individuality and dignity. They can no longer depend on their human ability to use normal defense mechanisms as a form of basic protection. They are placed under the direction of community authorities who are unaware as to what this patient has been through in the first place. These authorities condone the parent/child relationship idea because that justifies their employment and a reason to Lord over others in this sick society.

Respectfully,

Dorothy Miller

Dorothy Miller

Association of Mental Health Administrators
840 North Lake Shore Drive, Suite 1103W — Chicago, IL 60611, (312) 943-2751

WEIR RICHARD KIRK, F.A.C.H.A.
Executive Director

April 24, 1985

Senator Lowell P. Weicker, Jr.
303 Hart Senate Office Building
Washington, DC 20510

Dear Senator Weicker:

The Association of Mental Health Administrators (AMHA) would like to submit this statement as part of the record of the April 1-3, 1985 joint hearings on the institutionalized mentally disabled. AMHA is the national professional society for mental health administrators. Our membership includes chief executives from a variety of mental health facilities, both public and private and not-for-profit and investor-owned.

As evidenced in your 250-page report and by the many witnesses at your recent hearings, there are a number of problems which exist in state mental institutions. These problems involve patient abuse and neglect; staff abuse; inadequate staffing levels; inappropriate credentialing of some healthcare personnel; reduced and/or inadequate financial resources; uneven accreditation and/or certification procedures, etc. We recognize that these problems do exist, and, as the national organization for mental health administrators, we are dedicated to the improvement of these situations through, among other things, the development of better institutional administration. A good program requires not only good clinical personnel, but good administrative personnel as well.

Several of AMHA's formally stated aims and objectives specifically address this issue. They include:

(1) to enhance the attainment of mental healthcare and disability treatment goals through use of progressive and state-of-the-art administration within all levels of public and private care/treatment of the emotionally disturbed, mentally ill, developmentally disabled and those with problems of alcohol and substance abuse;

(2) to establish a standard of competence and promote excellence in mental health/disability administration;

(3) to provide and promote timely and pertinent formal education and continuing training to increase the competence of those who practice administration in the field of mental disabilities;

(4) to improve administrative practice and management through research studies and application, plus adoption of modern program evaluation techniques, by administrators and organizations in the field of mental disabilities;

(5) to cooperate and/or contract with other organizations, agencies and educational institutions to foster the objective of improving administrative practice in both generic and specialized health organizations providing mental health/disability care services;

We feel that our continued success in attaining these goals will help to reduce the frequency and occurrence of the type of adverse situations which your report documents. And, of course, our commitment to a high standard of excellence for mental health administrators applies across the board; it does not discriminate or favor those in private versus public institutions, or inpatient versus outpatient facilities.

The Association of Mental Health Administrators commends the Subcommittee on the Handicapped of the Senate Labor and Human Resources Committee and the Subcommittee on Labor/HHS of the Senate Appropriations Committee for its continued interest in the area of care for the mentally disabled. We appreciate the opportunity to comment on this important issue, and we would be happy to provide any further information that might be of assistance to the Subcommittees' members and their staffs.

Sincerely,

W. R. Kirk

Weir Richard Kirk, FACHA
Executive Director

WRK/mr

State of New Jersey
DEPARTMENT OF HUMAN SERVICES
CN 700 TRENTON, N.J. 08625

April 11, 1985

Honorable Lowell P. Weicker
Chairman, Subcommittee of the Handicapped
Committee of Labor and Human Resources
US Senate
Washington, DC 20510

Dear Senator Weicker:

The Subcommittee on the Handicapped is to be commended for sponsoring the April hearings on conditions in institutions for the mentally ill. Because mentally disabled persons often rely on the state for assistance and protection it is critical that these services be provided in an effective and caring manner.

I am therefore very concerned about testimony that was delivered before the Subcommittee alleging inadequate conditions in state psychiatric hospitals in New Jersey. Since the Chief Executive Officer of Trenton Psychiatric Hospital was not permitted to participate on the New Jersey panel before the Subcommittee, I am requesting that my written comments be entered in the record.

Although the Department is an umbrella agency that provides many needed services to approximately one million persons, I consider the provision of quality care in institutions to be our highest priority. One of my first acts as Commissioner in 1982 was the implementation of a plan to upgrade these facilities. An Office of Quality Assurance was established which regularly inspects these facilities and reports directly to me. All necessary resources were also allocated to these facilities to insure a high level of care to this vulnerable population.

Funding for all state psychiatric hospitals increased from $138.2 million in 1981 to $182.6 million in FY 1984, a 32 percent increase. Per capita expenditures increased from $104 to $142 during the same period. The contribution to these costs by the federal government in 1984 through Medicaid and Medicare reimbursement was $27 million compared to $138 million by the state.

These state actions resulted in the accreditation of all six psychiatric hospitals for the first time in New Jersey's history. Although some criticism was made at your hearings on the process used by the Joint Commission on Accreditation, I can assure you that their standards are extremely difficult to achieve. Of all the states that have three

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or more hospitals, New Jersey is one of only seven states which can claim that all institutions have received accreditation.

We were very surprised therefore to learn of the statements made by persons subpoenaed by the Subcommittee concerning abuses in our institutions. I was particularly concerned about allegations that were made by one of our staff who is a nurse on a medical review team. I immediately ordered an investigation of these conditions at Trenton Psychiatric Hospital, where most of the abuses allegedly occurred, as well as a review of the reports prepared by the medical review team.

These investigations (attached) found that most of the allegations were not justified nor were they included in the written reports prepared by the medical review team.

According to the Chief Medical Consultant for the Department, who made an unannounced visit recently to Trenton Psychiatric Hospital, "The only conclusion that can be drawn from this visit is that the patients have been well cared for, were comfortable, well nourished, protected and secure." Recently the State Police also released the findings of an unprecedented undercover investigation at Trenton Psychiatric Hospital conducted two years ago. According to the State Police Superintendent, "there was nothing to substantiate claims of patient assaults, abuse of patients or thievery from patients by staff members."

I realize that conditions at our hospitals are not perfect and welcome any suggestions to further improve them. For example, I have established on-site monitoring teams to insure that JCAH standards are met throughout the year. We have also accelerated our efforts to recruit more registered nurses at the institutions which was recommended at your hearing. However, all of the evidence I have indicates that, for the most part, the charges made against the state are not valid and represent a serious distortion of the care which is, in fact, provided.

In order to further improve the care provided in institutions, I strongly recommend additional federal support. As I have already indicated, the federal government's financial commitment to these patients is meager compared to the state's and does not nearly address the real need. Medicaid reimbursement is restricted to persons below 21 years old and above 65. Most of our patients are between 21 and 65 years old and are therefore denied any federal assistance. The federal government needs to do more if we are to move ahead as a nation to protect and serve all of the mentally disabled in institutions.

This also applies to federal support for community based mental health care. One of the problems that we face in our institutions is that discharges for our patients are often delayed because of insuffcient community services. Federal funding through the Alcohol and Drug Abuse and Mental Health Block Grant was reduced by 17 percent in 1981 and is still below the $12 million we received in 1980. In 1985 we plan to expend about $30.4 million in state dollars to fund about 106 community mental health agencies which should help to address the federal funding shortfall.

In conclusion, I look forward to the recommendations which will be made by the Subcommittee as a result of these hearings. We hope that one of them will be a renewed effort by the federal government to assist the states in meeting the needs of this population. As for New Jersey, I can assure you that we will continue our commitment to the mentally disabled and build on the substantial progress we have already made to establish a system of mental health services that is comprehensive, effective, and humane.

Sincerely,

George J. Albanese
Commissioner

GJA:13

TRENTON PSYCHIATRIC HOSPITAL

DIVISION OF MENTAL HEALTH AND HOSPITALS

NEW JERSEY DEPARTMENT OF HUMAN SERVICES

Written Testimony

To

SUBCOMMITTEE ON THE HANDICAPPED

COMMITTTEE ON LABOR AND HUMAN RESOURCES

THE HONORABLE LOWELL P. WEICKER, CHAIRMAN

UNITED STATES SENATE

APRIL 11, 1985

THE HONORABLE GEORGE J. ALBANESE, COMMISSIONER
NEW JERSEY DEPARTMENT OF HUMAN SERVICES

BY: FRANK G. CUOMO
CHIEF EXECUTIVE OFFICER
TRENTON PSYCHIATRIC HOSPITAL

MEDICAID REPRESENTATIVE TESTIMONY: "We have observed patients' food trays being removed untouched by the patient and no effort by staff to feed the patient."

TPH RESPONSE: Examination of the Periodic Medical Review (PMR) sheets which are completed on each individual reviewed by the PMR team resulted in no instance of the above quoted situation being observed at Trenton Psychiatric Hospital. Examples of the forms used by the PMR Team are included as attachments A.1 and A.2.

While not identified as a problem at Trenton Psychiatric Hospital, nursing staff routinely monitor the eating habits of all patients and report any variation to their supervisor from already known eating patterns. In addition, Trenton Psychiatric Hospital utilizes individuals of United Progress Incorporated, a federally funded program, to provide assistance for the feeding and monitoring of feeding of patients in the geriatric unit. Until January, 1985, TPH had the services of three (3) individuals from this program. These individuals worked four days per week and at least one individual was available for each meal those days. Since January, 1985, TPH has had the services of only one (1) of these individuals. The individual works 4 days per week from 7:30 a.m. - 12:00 noon each of those days. The hours this individual works allows additional coverage for breakfast and lunch. This individual has been trained by a Supervisor of Nurses (SON) from the Geriatric Unit in the appropriate assistance in feeding patients at this level, counseling of patients to cut foods appropriately, and to assist nursing staff in preparing snacks.

Trenton Psychiataric Hospital will continue to actively and aggressively utilize its internal resources (e.g. nursing personnel) as well as whatever appropriate external resources are available to insure that the situation mentioned above is never experienced by a patient under the care of this facility.

MEDICAID REPRESENTATIVE TESTIMONY: "Extra fluids are not provided."

TPH RESPONSE: While not entirely clear, it would appear that the statement of a need for extra fluids is based upon some observed physical condition or indication of a need based upon the documentation in the clinical record. Again, upon examination of the individual PMR sheets there is no indication of a perceived need for extra fluids by the Medicaid Representatives in their written comments, nor is there any indication of dehydration, a physical condition which would obviously dictate extra fluids.

Although the individual PMR reports and the final 1984 PMR report do not indicate TPH was deficient regarding the above issue, the Administration of TPH has initiated the development of periodic audits of intake and output documentation to insure that proper amounts of fluids are provided and taken by all patients.

MEDICAID REPRESENTATIVE TESTIMONY: "There is no collaboration between medical, nursing, or dietary to resolve dietary problems."

TPH RESPONSE: At the present time a full-time nutritionist is assigned to the geriatric unit at Trenton Psychiatric Hospital to facilitate collaboration between dietary and other disciplines. An integral part of the job description of this person is the requirement to attend treatment team meetings of those patients identified by the nutritionist, physician, or treatment team as needing nutritional intervention. It is during these meetings that collaboration and resolution regarding dietary problems takes place.

Additionally an impromptu inspection of the geriatric unit at TPH conducted 4/2/85 by a representative of the Department of Human Services and the Division of Medical Assistance and Health Services (Medicaid) found no evidence of malnutrition or nutritional problems in their examination of every patient residing in the unit at that time.

Further evidence of the attention paid to nutrition and the implication that collaboration among the multi-disciplinary must occur is reflected in the facts that: (1) 31 (25%) patients in the geriatric unit have been placed on special diets, (2) 27 (21%) of the patients in the geriatric unit are on some type of nutritional supplement.

It would appear based on the above information that the statement regarding no collaboration is at best a gross over generalization and is not validated by other information.

MEDICAID REPRESENTATIVE TESTIMONY: "Many times patients who are incontinent are forced to eat their meals in that state."

TPH RESPONSE: There is no indication on the individual PMR reports, the final yearly PMR report, or through any discussion with a Medicaid Representative of the above situation having been observed or a problem at Trenton Psychiatric Hospital. The Administration of TPH views the above as totally unacceptable care and is confident the testimony offered regarding this situation was not related to TPH.

MEDICAID REPRESENTATIVE TESTIMONY: We have not observed any real individualized toilet-training programs".

TPH RESPONSE: Trenton Psychiatric Hospital has developed a Bowel and Bladder Program which includes appropriate documentation forms (Attachment C-1 and 2). Staff have been trained in the appropriate implementation of this program and the program is presently operative in the geriatric unit. The development and implementation of this program was in response to issues mentioned in the formal 1984 PMR report and provides an example of Trenton Psychiatric Hospital's willingness to utilize constructive criticism in the development of the highest quality of service for patients under its care.

MEDICAID REPRESENTATIVE TESTIMONY: "Those patients retaining some stage of continency are not walked to the bathroom unless they are able to do so themselves."

TPH RESPONSE: There has been no mention of the above situation at TPH in the individual PMR reports, the final yearly PMR reports, or in discussions with Medicaid Representatives. Therefore, the supposition is made that the statement is not relevant to conditions at TPH.

The reason such a situation was not observed at TPH is due to the proactive approach Administration and Staff at TPH have taken regarding provision of the highest quality of care possible. This is indicated by

(1) The obvious caring of staff at TPH for the patients they serve. Most recently positive comments in this regard were forthcoming by the physician conducting the federally mandated medicare survey (3/25, 3/26, 3/29, and 4/1/85). In addition, a surprise independent survey of the geriatric unit by physicians from the Department of Health and Medicaid on April 2, 1985, resulted in high praise for the obvious caring of staff for patients and the excellent physical condition of those patients.

(2) Trenton Psychiatric Hospital is fully accessible to the handicapped thereby providing those patients who do have difficulty ambulation, the opportunity to maintain their independence and dignity whenever and whenever possible.

(3) Relatedly, each patient's room in the Geriatric Section at TPH has its own bathroom to provide easy access for individuals.

MEDICAID REPRESENTATIVE TESTIMONY: "In one of the Institutions, we observed one female with a distended bladder and ignored by staff until we mentioned it and yet there was no documentation in the chart concerning the problem."

TPH RESPONSE: There is no indication from the testimony given by the Medicaid Representative that this observation was made at Trenton Psychiatric Hospital. Futhermore, examination of the individual PMR reports, yearly final PMR reports, or notes from discussions with Medicaid Representatives revealed no mention of the above situation.

MEDICAID REPRESENTATIVE TESTIMONY: "Fecal impactions are a daily occurrence and there is no connection in the institutions staff's minds between impactions, diets, fluids, exercise which are a common method of preventing these. There is no association between diet, fluids, and malnutrition. They do not recognize the signs of malnutrition. There is no relationship between diet, consumption of food and weight loss."

TPH RESPONSE: None of the documentation provided Trenton Psychiatric Hospital by Medicaid Representatives, i.e.,individual PMR's and yearly final PMR's, supports the contention that staff at TPH are not aware of the relationship between intake in the form of diet and fluids and its relation to and interaction with the physical and psychiatric status of patients.

On the contrary, information provided previously, e.g., assignment of a full-time nutritionist to the geriatric ward, 25 percent of patients on special diets, 21 percent of patients on nutritional supplements, would suggest that staff are well aware of the relationships mentioned in the testimony.

MEDICAID REPRESENTATIVE TESTIMOMY: "They are supposed to take monthly weights and you can see patients losing as many as 10 to 15 pounds and yet there is no concern about it. Malnutrition is a common condition in the elderly on the medical wards. Significant weight loss is not treated until the patient is in a malnourished state and by that time, they have a multitude of problems."

TPH RESPONSE: Examination of the individual PMR reports revealed no reviewer comments of any patient losing as much as 10 to 15 pounds. In one instance, a patient who was known to have cancer, had gained 13 pounds and lost 15 pounds for a net loss of 2 lbs. The Medicaid Reviewer's comments on the individual PMR dated June 12, 1984 are: "Patient has problem with weight. She is 2 lbs. less than when she was admitted last June. No followup to this weight loss." The staff because of the physical diagnosis of the patient were and are well aware of her nutritional state and monitor such closely.

One of the 77 individual PMR reports on the over 65 population completed by Medicaid Representatives indicated malnourishment as a problem. This case has been followed up by the Administration of TPH and has been determined not to be malnourished and in fact, has gained 11 pounds within the last 9 months. In addition, during a survey of each and every patient on the geriatric unit at TPH by physicians representing the New Jersey Department of Health and Medicaid on April 2, 1985,(Attachment C-3 and 4) no instance of malnutrition was found. On the contrary, the physicians had high praise for the staff regarding the overall health of the patients.

Finally, it is well documented that malnutrition among the elderly is related to a wide variety of physical problems. One very common problem is decubitis. Trenton Psychiatric Hospital through quality physical care and good nutritional intervention, has gradually reduced the incidence of decubitis to the point that there have been no instance of decubitis at Trenton Psychiatric for the last three (3) months.

MEDICAID REPRESENTATIVE TESTIMONY: "After the 1983 PMR at Trenton Psychiatric Hospital, I had a meeting with the nursing supervisors and the Assistant Director of Nurses and I was appalled because the supervisors informed me that on a particular floor there was never enough food to go around to all the patients so that meant that usually at one meal there were at least 12 to 15 patients who did not eat at all. This occurred at every mealtime."

TPH RESPONSE: The allegation as stated has never been brought to the attention of officials of Trenton Psychiatric Hospital either through the individual PMR reports, the yearly final PMR, or discussions with any Medicaid Representative. The Administration of TPH is quite confident that the nutritional quantity and quality of meals served all patients exceeds acceptable state and federal criteria.

If the allegation as stated were true one could expect a significant number of malnourished patients and the accompanying physical problems (decubitis, etc.)

In fact, during a recent (4/2/85) surprise visit by physicians representing the Commissioner of the Department of Health and the Division of Medical Assistance and Health Services (Medicaid) not one case of malnourishment was identified during their examination of every patient residing in the geriatric unit. Additionally, TPH has not had one instance of decubitis during the calendar year 1985.

Finally, no nursing personnel remember such a statement being made to any Medicaid Representative although the possibility exists that the employees are no longer employed at TPH.

MEDICAID REPRESENTATIVE TESTIMONY: " We see extremely obese adolescents, whose obesity obviously effects their mental health, and they themselves are requesting special diets, yet they do not receive dietary counseling".

TPH RESPONSE: An analysis of all adolescents presently at TPH identified five 5) individuals as obese. Examination of each chart by the Unit Administrator and rechecked by a Hospital Administrator verified documentation of dietary counselling in each case. Copies of the documents relating to each case have not been attached so that the rights of the patients regarding confidentiality were not violated.

MEDICAID REPRESENTATIVE TESTIMONY: " Adaptive equipment is lacking".

TPH RESPONSE: While an analysis of the individual PMR reports did not identify anyone as needing adaptive equipment, Trenton Psychiatric Hospital has available to any patient perceived as needing adaptive equipment a wide range of items related to activities of daily living (ADL). Attachments B1 thru B6 provides copies of purchase orders for such adaptive equipment.

MEDICAID REPRESENTATIVE TESTIMONY: "Many times patients who are incontinent are forced to eat their meals in that state."

TPH RESPONSE: There is no indication on the individual PMR reports, the final yearly PMR report, or through any discussion with a Medicaid Representative of the above situation having been observed or a problem at Trenton Psychiatric Hospital. The Administration of TPH views the above as totally unacceptable care and is confident the testimony offered regarding this situation was not related to TPH.

MEDICAID REPRESENTATIVE TESTIMONY: We have not observed any real individualized toilet-training programs".

TPH RESPONSE: Trenton Psychiatric Hospital has developed a Bowel and Bladder Program which includes appropriate documentation forms (Attachment C-1 and 2). Staff have been trained in the appropriate implementation of this program and the program is presently operative in the geriatric unit. The development and implementation of this program was in response to issues mentioned in the formal 1984 PMR report and provides an example of Trenton Psychiatric Hospital's willingness to utilize constructive criticism in the development of the highest quality of service for patients under its care.

MEDICAID REPRESENTATIVE TESTIMONY: "Those patients retaining some stage of continency are not walked to the bathroom unless they are able to do so themselves."

TPH RESPONSE: There has been no mention of the above situation at TPH in the individual PMR reports, the final yearly PMR reports, or in discussions with Medicaid Representatives. Therefore, the supposition is made that the statement is not relevant to conditions at TPH.

The reason such a situation was not observed at TPH is due to the proactive approach Administration and Staff at TPH have taken regarding provision of the highest quality of care possible. This is indicated by

(1) The obvious caring of staff at TPH for the patients they serve. Most recently positive comments in this regard were forthcoming by the physician conducting the federally mandated medicare survey (3/25, 3/26, 3/29, and 4/1/85). In addition, a surprise independent survey of the geriatric unit by physicians from the Department of Health and Medicaid on April 2, 1985, resulted in high praise for the obvious caring of staff for patients and the excellent physical condition of those patients.

(2) Trenton Psychiatric Hospital is fully accessible to the handicapped thereby providing those patients who do have difficulty ambulating, the opportunity to maintain their independence and dignity whenever and whenever possible.

(3) Relatedly, each patient's room in the Geriatric Section at TPH has its own bathroom to provide easy access for individuals.

MEDICAID REPRESENTATIVE TESTIMONY: "In one of the Institutions, we observed one female with a distended bladder and ignored by staff until we mentioned it and yet there was no documentation in the chart concerning the problem."

TPH RESPONSE: There is no indication from the testimony given by the Medicaid Representative that this observation was made at Trenton Psychiatric Hospital. Futhermore, examination of the individual PMR reports, yearly final PMR reports, or notes from discussions with Medicaid Representatives revealed no mention of the above situation.

MEDICAID REPRESENTATIVE TESTIMONY: "Ambulation programs are lacking. Patients are contracted like pretzels, and from experience I know that did not happen overnight."

TPH RESPONSE: Review of comments on the individual PMR reports and the final yearly PMR reports revealed no comment or statement of any patient contracted like a "pretzel". Additionally, during the survey conducted by physicians from the New Jersey Department of Health and Medicaid on 4/2/85, there was no indication of any patient showing severe muscle contractions from lack of ambulation. Again to reiterate, the physicians were lavish in their praise of the overall condition of the patients on the geriatric unit at TPH.

Trenton Psychiatric Hospital contracts with a private vendor for the delivery of physical therapy programs. The program is located in the Raycroft Building(Geriatric) on the grounds of TPH. Statistics for the most recent quarter(Jan.-Mar 1985) indicated that a total of 37 patients on the geriatric unit are receiving physical therapy interventions. These treatments include gait training, whirlpool, ultrasound, therapeutic exercises, moist heat/cold pac, etc. During the quarter there have been a total of 1886 individual patient visits/treatments.

The great majority of these treatments have been provided to the geriatric patients. In addition, the physical therapists provide direction and guidance to nursing personnel so that they may reinforce the physical therapy treatment regime when assisting patients with their activities of daily living.

The contractual arrangement between Trenton Psychiatric Hospital and the private vendor allows TPH to provide a much greater range of physical therapy interventions and higher quality of physical therapy than would be possible if TPH were required to deliver the service internally.

Again it would seem logical that if ambulation programs were lacking in the elderly population, 'certain' physical problems would be evident, especially decubitus. As mentioned previously that is not the case due to staff's attention to those nutritional and ambulation factors contributing to the development of decubitus ulcers. In fact, the policy and procedure related to decubitus prevention developed by Trenton Psychiatric Hospital has received praise from the Medicare Representative during Trenton Psychiatric Hospital's most recent survey. Attachments F1 thru 6 provides copies of the decubitus policy and procedure in operation at Trenton Psychiatric Hospital.

MEDICAID REPRESENTATIVE TESTIMONY: "They are sheet restrained in their chairs all day long and never repositioned or permitted to stretch out on their beds".

TPH RESPONSE: Under no circumstances are sheet restraints used at Trenton Psychiatric Hospital. In fact, TPH maintains a policy and procedure that distinguishes therapeutic interventions to be utilized when saftey measures are implemented 'to protect the convalescing geriatric or handicapped patient. This policy on Protective Therapeutic Supports (attachment G1 and 2) has received accolades from Medicaid Representative during their recent Periodic Medical Review at Trenton Psychiatric Hospital. This policy emphasizes the importance of care to be given to patients while therapeutic supports are in place. Documentation occurs via the use of a log(attached to policy) that is incorporated into the clinical record noting nursing actions taken to insure that the patient is regularly ambulated, skin checked, toileted, etc.

MEDICAID REPRESENTATIVE TESTIMONY: "Activities are non-existent. Staff are observed putting a book together or playing scrabble alongside the patient, but there is no interaction between the staff and that patient."

TPH RESPONSE: The Administration of Trenton Psychiatric Hospital categorically rejects the statement that activities are non-existent. In fact, the statement made by the Medicaid Representative during testimony is somewhat contractory to a statement included in the formal PMR report conducted on June 28, 1984, and submitted to Trenton Psychiatric Hospital on August 24, 1984. The statement reads, "Improvement has been made in medical progress notes and off ward activities". (Page 10)

In addition, the Rehabilitation Services Department at Trenton Psychiatric Hospital maintains monthly statistics regarding the types of activities provided by Rehabilitation Staff as well as the number of patients served and the number of direct patient contact hours.

Enclosed as attachments D1 thru 9 are copies of the statistics compiled for the month of February 1985. The statistics do not support the statement that therapies are non-existent at TPH. In fact, the statistics provided indicate an active and extensive program of both on/off ward activities, especially in the geriatric(Raycroft) and adolescent sections. Not reflected in the statistics, but equally important is the fact that staff deployment is such to allow many activities to occur during evening and weekend hours. Attachments E1 thru 3 are copies of recreation activities schedules for the adolescent(Lincoln) unit which provide examples of the activities provided during evening and weekend hours. The data presented is only for the Rehabilitation Services Department which, while a significant portion is not the total therapeutic program provided patients at TPH. Nursing programs such as remotivation and bowel and bladder training, as well as psychology groups are just two more examples of the wide range of activities offered by Trenton Psychiatric Hospital.

The Administration of Trenton Psychiatric Hospital has consistently strived to achieve the total potential of the human and material resources to meet the demands of the population and agencies it serves. While recognizing the fact that many improvements remain to be achieved, the Administration and staff of TPH are proud of the strides made toward delivery of quality care to the patients we are mandated to serve.

MEDICAID REPRESENTATIVE TESTIMONY: "There is an overuse and misuse of seclusion and restraint in the elderly as well as the adolescents. It is particularly disturbing seeing young people's behavior not properly managed and the lack of evaluation by a professional to determine whether seclusion or restraint is needed in a given situation", "We never see any notes or documentation concerning aggressive behavior and how it's treated."

TPH RESPONSE: Trenton Psychiatric Hospital does not utilize seclusion with its elderly population. Additionally, as stated earlier, the geriatric unit has a well developed policy and procedure for Protective Therapuetic Supports which are most often used in place of restraints.

Seclusion and/or restraint at Trenton Psychiatric Hospital are only to be used as a temporary emergency therapuetic restriction when less restrictive measures have failed to control a patient's dangerous behavior. Policies and procedures exist (Attachments H1 - H6) that specifically outline steps staff must follow to ensure the safety and dignity of patients. In all instances of seclusion/restraint a physician must evaluate the condition the patient's clinical condition prior to the actual seclusion. In those instances of emergency where a physician is not immediately available a clinically priviledged staff member may initiate seclusion/restraint but must acquire a written physician's order within one hour of initiation. Seclusion/restraint instances are **temporary emergency therapuetic measures** which are employed only when a patient has attempted to seriously harm him/herself or others. They are time - limited and may not exceed twenty-four hours without the approval of the Medical Director. A log is kept each time a patient is secluded/restrained which documents regular periodic (every 15 mins.) checks of the patients condition, administration of medication, tolieting, provision of meals, fluids, etc.

Trenton Psychiatric Hospital has been very pro-active in its efforts to protect the rights and dignity of patients prior to, during, and after the need to seclude/restrain. As part of this aggressive approach TPH has instituted a number of internal mechanisms to insure the identification, monitoring, evaluation, and remediation of problems regarding the use of seclusion/restraint. These mechanisms have included: .

1. A multidisciplinary group defined a clear set of standards for the appropriate utilization of seclusion/restraint, based on existing hospital policy. The emphasis was on the clinical justification for the use of seclusion or restraint. (April - June, 1984)
2. A hospital-wide evaluation of seclusion/restraint was conducted (July, 1984).
3. Evaluation results were presented to the Quality Assurance Committee and recommendations were made. Each Complex Administrator received evaluation results and were required to develop remediation strategies in response to problems identified in their Complex. (August - September, 1984)
4. Plans for remediation were developed in consultation with QA Staff (September, 1984).

As an outcome of these internal processes and external review mechanisms, TPH has responded by incorporating a number of recommendations and has revised its seclusion/restraint policy three times within the last four (4) years. Attachments H.1 through H.6 are copies of past and present seclusion/restraint policies at TPH.

In addition to the above stated internal measures at TPH in general, the Lincoln Complex has devoted additional energies and resources to seclusion/restraint procedures with the adolescent population. Trenton Psychiatric Hospital has recognized the need to make special and extra efforts to insure the safety of this population. This process includes:

1) The use of less restrictive measures prior to the use of seclusion/restraint.
2) The clients behavior is assessed by a professional, most often a physician, although in an emergency a clinically privileged registered nurse may authorize seclusion/restraint based on her assessment. A written physician's order must be obtained within one hour in those instances.
3) Counselling is provided during the restraining/secluding instance most often by the primary therapist or physician. The counselling includes a clear statement of behaviors required to expedite release.
4) The patient's treatment team must review every seclusion/restraint instance to address issues of treatment changes or additions which would help prevent future seclusion/restraint incidents.

To insure that the above procedures are carried out appropriately the Adolescent Unit at TPH has instituted their own internal audit of seclusion/restraint incidents (Attachment I). These audits are begun by a Registered Nurse as soon as possible subsequent to the incident. The Adolescent Unit's own Incident Review Committee utilizes these audits in their review of every seclusion/restraint instance.

The Adolescent Unit at Trenton Psychiatric Hospital also recognizes the need to support staff in their attempts to learn and implement less restrictive interventions when dealing with this population. These support actions include:

1) The assignment on a full-time basis (9/1/84) of a Coordinator of training within the Adolescent Unit. Primary assignment is to continue the Crisis Recognition, Prevention, and Intervention Training (CRPI) begun 6/84 on this unit. This training provides skills directly related to the handling of potentially explosive situations, with particular emphasis upon de-escalation techniques to avoid having to resort to seclusion/restraint.
2) Clinical Specialists in Psychiatric Nursing assigned to the Adolescent Unit have developed and implemented a training program for professional and direct care nursing staff. The focus of this training program which started 8/84 is upon limit-setting techniques, differentiation of normal vs. abnormal adolescent behavior, introcution and application of certain behavioral techniques (contracting, time-out, etc). Examples of the curriculum for the training are included as Attachment J.
3) Both the Division of Mental Health and Hospitals and the Administration of Trenton Psychiatric Hospital are supportive of efforts to improving staff-patient ratios within the Adolescent Unit. It is felt that this will have a positive impact upon the goal of reducing seclusion/restraint incidents to an absolute minimum and to insure the dignity of patients when seclusion/restraint cannot be avoided.

4) Relatedly, the Division of Mental Health and Hospitals has supported and approved a proposal made by TPH and Adolescent Administrators to hire employees in the job classification of Youth Worker. The job description and duty expectations (Attachment K) are more specific to the needs of an in-patient adolescent population. The new position was announced in March 1985 and applicants are currently being interviewed by the Unit Administrator of the Adolescent Unit.

It is felt that these aggressive pro-active measures by the Division of Mental Health and Hospitals, Trenton Psychiatric Hospital, and the Adolescent Unit at TPH will insure an environment which is safe, secure, protective of human rights and therapeutic.

The Commonwealth of Massachusetts
Executive Office of Human Services
Department of Mental Health
160 North Washington Street
Boston, Massachusetts 02114

James J. Callahan, Jr., Ph.D.
Commissioner

AREA CODE 617

March 29, 1985

The Honorable Lowell Weicker, Jr.
Chairman, Subcommittee on the Handicapped
United States Senate
Washington, D.C. 20510

Dear Senator Weicker:

I am pleased to respond to your letter of February 20, 1985 regarding your inquiry into conditions for residents and staff of state facilities for the mentally disabled. The issues you have raised are extremely significant ones for those of us who work in human services as well as for the clients, families, and communities we serve.

Western Massachusetts has one public facility for people with mental illness. The population at Northampton State Hospital today is 194 residents. Of that number, 171 people are currently served on psychiatric wards; 23 people are elderly and are served apart from the general psychiatric population. We do not routinely admit people with mental retardation; adolescents under age 16; or adolescents between 16 and 21 who are eligible for special education services.

It is important to note that western Massachusetts has developed an extensive range of community services as a result of a federal consent decree signed in 1978 (Brewster v. Dukakis, civil action number 76-4423-F). We use the hospital primarily for the provision of a secure setting and rapid stabilization. We are currently in the process of implementing community residential and day programs for sixty-six adults who have had lengthy stays at Northampton due to the lack of community alternatives in the past. When those placements are completed, we expect our census to be in the 100-120 person range.

I mention this background information to you because of its implications for the type of client now served in the hospital:

1) Clients who can be assisted by the provision of emergency services or other supports in the

community are not admitted to the hospital. (This may include people with aggressive behavior);

2) Clients admitted to the hospital are more likely to be more seriously mentally ill;

3) Treatment at the hospital is focused on stabilization and return to an appropriate community setting.

It is our experience that staff can be effectively trained to handle violent situations. For several years now, we have used a certification program directed at teaching staff how to first diffuse a potentially violent situation and, if necessary, to humanely and safely restrain an individual. This teaching process has been enormously effective not only in giving staff specific competencies but in helping them develop an understanding of aggressive behavior and how to provide reassurance and support to clients before violence becomes an issue.

The legislature of the Commonwealth has recently passed Chapter 464 of the Massachusetts General Laws (attached) which regulates the use of seclusion and restraint in state facilities. This law requires both trained staff and specific monitoring actions. The law is effective April 7, 1985; we expect it to be an additional safeguard.

Clients at Northampton State Hospital are protected by the Department of Mental Health's regulations on complaints, the existence of a local human rights officer, and a departmental Office of Human Rights which reports directly to the Commissioner. I will be most pleased to send you additional information on these three avenues for client rights, if it would be helpful to you. In addition, the Center for Public Representation provides on-site legal advocacy at the hospital. An external monitoring group comprised of members of the Western Massachusetts Alliance for the Mentally Ill makes regular inspection visits at the hospital to identify situations that might be either uncomfortable (e.g., quality of the food, environment, etc.) or unsafe for the clients.

In summary, I would like to emphasize that it is our consistent experience that aggressive behavior can be safely and effectively controlled by trained staff; strict guidelines for intervention; strong oversight of client rights by internal and external mechanisms; administrative oversight; and by the availability of sufficient and appropriate community services that divert people from unnecessarily restrictive hospitalization and provide them with suitable living and work situations when hospitalization is no longer required. The expertise of many of our community staff (who receive identical training in restraint to that provided at the hospital) allows clients with potentially aggressive behaviors to reside in the community without harm to themselves or others.

Please let me know if I can be of further assistance to you. We look forward to the conclusions reached as a result of these hearings.

Sincerely,

Elizabeth Jones
District I Manager

EJ/w

Attachment

Testimony to the Senate Subcommittee on the Handicapped by the Assault Prevention Training (APT) Project of Columbus, Ohio.

People labeled as disabled are at high risk for physical, sexual and verbal assault, whether they reside in the community, in an institution, or in a smaller residential facility.

Although American society has responded to people labeled as mentally ill or mentally retarded in a well-intentioned way, our history of dealing justly with this population is far from the ideal. Traditionally, persons who are labeled as disabled have been isolated from the greater community. Institutions as places of safety have been established to care for persons considered disabled. Our society's rationalization of protectionism serves the overt purpose of keeping people considered incapable of caring for themselves away from the evils of that society. The consequence of this protectionistic policy is that people with disabilities are isolated and placed in a controlled environment.

People in this type of controlled setting are often bereft of meaningful relationships. Peers and workers in their lives come and go, with little control of persons involved.[1] It is difficult to feel autonomous under conditions that do not enhance self esteem and personal ability to problem solve, or that reinforce learned helplessness. Ironically, there is evidence that people with disabilities, isolated for their own protection, may be less safe than if society had not benevolently intervened.

Seattle Rape Relief, a project working with children considered developmentally disabled, indicates that 99% of assaults against these children were perpetrated by relatives, friends, acquaintances or caregivers of the survivor. They estimate that up to 30,000 cases of sexual exploitation involving disabled persons occur each year in Washington State alone.[2] This study indicates that many people labeled as disabled are being isolated with those who are assaulting them, without acquisition of skills that will enable them to recognize and possibly avert a dangerous situation. There may be little formal or experiential learning taking place that would increase independence and self-esteem, thereby decreasing vulnerability to assault.

People who depend on caregivers or social service agencies for their survival quickly learn to comply in order to get their needs met. An innate power imbalance exists in a situation where two groups of people have opposing roles of those who 'care for' and those who are 'cared for'. Whenever there is unequal control there is a chance that power may be abused and the person relegated dependent status may be exploited or assaulted.

Someone considered to have a physical or mental disability is perceived to be an easy target. People who are labeled as disabled are among the least powerful groups in our society. There are few statistics dealing with assault and people labeled as disabled. This fact in itself is a reflection of how our culture devalues this group of people.

A few available statistics, however, indicate that people labeled as physically or mentally disabled are a vulnerable population, and that more work needs to be done in order to understand the relationships between disabilities and experiences of abuse. Dr. Mark Souther, in a study of 125 children receiving protective services, found that 69% of the children were found to have one or more disabilities.[3] Carmen, Rieker and Mills found, in a recent study of 188 male and female psychiatric inpatients, "a clear link between abuse experiences and psychiatric illness".[4] Stark, Flitcraft and Frazier found that women who had been battered presented a much higher rate of behaviors that are labeled deviant, including suicide and substance abuse. In all but a few cases, these problems emerged only after the onset of abuse.[5]

Labels such as "deviant behaviors" and "mental illness" are methods some people choose to deal with assault they have experienced.

However, their assault history may not be dealt with in a traditional treatment setting. Whether or not an individual is an assault survivor, when a person takes on a social role of a person labeled mentally ill, they are at high risk for assault. Physical or mental disabilities heighten a person's vulnerability; the person labeled mentally ill is often isolated, dependent on others for significant areas in their lives, and lacking in feelings of self worth.

Traditional methods of preventing abuse based on strategies that foster isolation, powerlessness or learned helplessness are not effective. Prevention and intervention for assault survivors relies on people having accurate information about assault and violence in our culture. Misinformation that promotes stigma and 'disabilityism' must be confronted. We need to look at the way we have been socialized, and the cultural messages we are all bombarded with. Alternatives to an aggressive society must be implemented; we and our children must have positive outcomes that build self-esteem and a social structure that values all members.

The APT (Assault Prevention Training) Project is designed to promote independence and decrease isolation of persons labeled mentally ill or mentally retarded/developmentally disabled. APT's goals are the personal empowerment of persons labeled as disabled, and the building of strong peer support networks and community support networks. A basic belief of the project is that information is power; if people labeled as disabled are given information and strategies of assertion to recognize and avert a potentially dangerous situation, then the greater community will be empowered as well. Prevention of assaults against people labeled as disabled will not happen by expecting others to care for this class of people. Prevention of assaults will happen by giving information and strategies of empowerment to people labeled as disabled, so they can begin to see themselves as strong and capable, and from there become people who are strong and capable.

April 5, 1985
Submitted by

Maureen Crossmaker   Dr. David Nibert
APT Coordinators

Assault Prevention Training Project
P.O. Box 02084
Columbus, Ohio 43202
(614) 291-2540

Footnotes

1. Wolfensberger, Wolf A Model for a Balanced Multicomponent Advocacy Protective Services Scheme

2. Seattle Rape Relief, Developmental Disabilities Project. 1825 South Jackson, Suite 102, Seattle, WA 98144

3. Souther, Mark D. Developmentally Disabled, Abused and Neglected Children: A High Risk/High Need Population, Perspectives on Child Maltreatment in the Mid '80s. U.S. Dept. of Human Services, NCCAN DHHS Pub. No. (OHDS) 84-30338 1984

4. Carmen, Elaine; Rieker, Patricia; Mills, Trudy Victims of Violence and Psychiatric Illness American Journal of Psychiatry 141:3, March 1984

5. Stark, Evan; Flitcraft, Anne; Frazier, William Medicine and Patriarchal Violence: The Social Construction of a "Private" Event, International Journal of Health Services, Vol. 9, No. 3 1979

APR 8 1985

1028 - 9th Terrace
Pleasant Grove, AL 35127
April 2, 1985

Honorable Lowell P. Weicker
United States Senate
Washington, D. C. 20510

Sir:

With regard to the hearings you are holding on the subject of abusive conditions in mental hospitals, please print the enclosed seven page letter from me to Governor George C. Wallace of Alabama in 1971 in the record of these hearings.

Thank you.

Yours truly,

James E. Wamble, Jr.

James E. Wamble, Jr.

Suit was filed against the Bryce - Searcy Hospital in the Federal District Court in 1971-72 at which time it was discovered that electric cattle prods were used in certain parts of the hospital.

Route 1, Box 51
Orrville, Alabama 36767
August 16, 1971

Honorable George C. Wallace
State Capitol
Montgomery, Alabama

Dear Governor Wallace:

Recent activities by the federal government relating to our state mental institutions have come to my attention through the newspapers and television. As a former patient I read them with keen interest. It is obviously difficult for the governor and the understaffed legislature to monitor the internal functioning of these institutions on a continuous basis from year to year and to issue such corrective instructions as should be necessary from time to time. The abuses detailed in this letter are not easily detected as a governor walks through our mental facilities because they can easily be discontinued for a brief duration only to be resumed when the governor leaves.

After reading this letter you will see why the writer feels that sweeping changes not involving bricks and mortar or the hiring of more staff are in urgent need of implementation. These defects will inevitably be revealed by the federal government in the process of their pending investigation. As a proud Alabamian I feel that we have sufficient determination to change these things ourselves as they are in the province of our duty to do so. The writer would like to recommend that a state investigative commission be appointed by the governor to study in detail procedures in the internal management of our state mental institutions and to issue such corrective recommendations as would appear proper.

As a patient at Bryce Hospital for eighteen months in 1962-63 the writer observed manifold examples of internal mismanagement, some of which are detailed in the following items. They are written in recommendation form and would probably approximate many of the recommendations a commission would produce after diligent and meaningful investigation.

ITEM 1 - The hospital staff should be ordered to cease involuntary detention of persons who are not a threat to the health and safety of the public. The institutionalization of these persons—who are in the majority in our mental institutions—should be allowed to continue only by their own consent. The practice of forbidding these persons from signing themselves out of the hospital should be ordered stopped. A woman patient at Bryce told the writer that in California where she had previously been a patient they were allowed to sign themselves out of the hospital if they wished. Investigation should be made as to whether the highest quality mental

(continued)

hospitals in the nation (such as Meninger in Kansas) allow such patients to sign themselves out. If such is the case, then Bryce should be ordered to follow suit. In order for a person to be held against his will--even for treatment that is of a high quality by today's standards (which is not the case at Bryce)--sufficient safeguard procedures of due process should exist to absolutely insure a person cannot be held unless he is a menace to the health and safety of the public. A stringent burden of proof should be placed on the proper parties to show that it is proper for a person to have his liberty denied him. The testimony of a doctor who has not even seen or consulted the potential patient should not be considered valid as it now is. The testimony of persons--such as certain family members or others--who have a vested financial interest in the detention of a person should not be considered valid. As you know, the vast majority of Bryce patients have been committed without being declared legally insane.

ITEM 2 - The hospital officials should be ordered to remove the bars and grills from the windows and porches--embedded in concrete though they be--except in the quarters of that relatively small percentage of patients who pose a threat to the health and safety of the public. The excuse for not removing them recently offered by certain of the hospital staff is a sham. With only one large box of hacksaws the patients so confined would gladly provide labor for removing these bars from the entire hospital in less than an hour. These bars harm the patients by making them feel restricted and trapped and produce hazards to human life in case of fire.

ITEM 3 - The hospital management should be ordered to dismiss all unlicensed physicians. Foreign unlicensed doctors from Cuba, Mexico, or elsewhere should not be allowed to practice the treatment of physical illnesses, much less mental illnesses.

ITEM 4 - Physicians who do not have psychiatric residency training should be ordered to stop administering traumatic "therapeutic" procedures such as electroshock or insulin shock. Medical doctors who are trained only as general practitioners are not qualified to monkey around with mental disorders in this manner.

ITEM 5 - The hospital staff should be ordered to cease allowing attendants or any hospital staff members other than resident-trained psychiatrists any influence in the selection of patients for the electroshock "therapy" list. This incredibly improper phenomenon of subprofessional discretion in the administration of electroshock "therapy" is mentioned on page 149 of the book entitled The Mentally Disabled and the Law. Some of the attendants that make these decisions have only an eighth grade education. Although the writer was extremely fortunate not to get into an abominable situation where an attendant placed him on the shock list at his discretion, patients who had been under

(continued)

other doctors in other wards told him it had happened to them. In 1967 a former Bryce patient told the writer an attendant who was fond of him managed to get him off the shock list. The misuse of electroshock "treatment" in this manner is a powerful tool for the maintenance by a reign of terror of what can only be described as "a state within a state" such as exists in our mental institutions. Most patients are terrified of shock treatments. Those who are not are certainly the exception and not the rule. Some medical doctors themselves consider shock treatments not as a valid form of treatment but as a form of torture (The Mentally Disabled and the Law, page 149).

ITEM 6 - The hospital officials should be ordered to cease requiring patients to turn in their outgoing mail unsealed as they did when the writer was a patient and they should be forbidden from opening, reading, analyzing or censuring any outgoing patient mail. They should likewise be ordered to cease opening incoming letters to patients and should be allowed to open only incoming parcels which might contain firearms or other weapons mailed in from outside sources.

In 1962-63 when the writer was in Bryce outgoing patient mail was read by the hospital staff. The writer sent his first letter home asking that the family come and get him and describing some of the abominable conditions. His mother says she never received any such letter. He soon learned that it was extremely unwise to continue making such appeals in writing. Other fellow patients complained to him that similar letters they had written never reached their destinations. Had this mail been allowed to flow freely the wretched conditions would have been more widely known and a public demand for corrective action might have developed. The patient's feeling of security gained in knowing his written communication with the outside world is not hindered should take precedence over the psychiatric "analysis" value which theoretically might be gained by staff reading of patient mail even if the staff were trained which they are not.

ITEM 7 - The hospital staff should be ordered to set up a system for the diagnosis and treatment--in person by a medical doctor--of any patient who contracts a physical illness on a weekend. During the writer's stay the medical doctors left on the weekends and did not return until the following Monday. Some of the most serious physical illnesses of patients went unattended.

One weekend the writer began running a fever of about 102° and became so weak he could barely stand up. No physician was available to provide medical attention. His ward attendant phoned a physician at home who directed by proxy that a shot be administered. The minimum educational requirements of the attendant who gave the shot was an eighth grade education. From then on the writer harbored a fear of becoming seriously ill at Bryce on the weekend and not having medical treatment at hand. To his memory no physician ever appeared on the weekend on any of the seven different wards where he was eventually assigned during his eighteen month stay.

A fellow patient who slept in a bed near the writer woke up early one Friday morning after discharging what appeared to the writer to be about a pint of blood into his clothing. Upon removing the clothing and discovering

(continued)

that they were soaked with blood he became extremely fearful and went to the attendant. No medical attention was forthcoming. Fortunately for him he stopped bleeding automatically because it was the following Monday--three days later--before he was examined by a doctor. He was 65 and said he went around in a state of constant fear that he would become seriously ill on the weekend.

He related to me an incident he witnessed personally that happened as follows: One weekend night right after the lights had been turned out on his ward one of his fellow patients rolled off the bed in severe pain and began rolling around on the floor, holding his hands over his right lower abdomen and moaning loudly. No medical attention was forthcoming. Two or three of the other patients on a ward which contained about eighty or ninety packed in sardinelike fashion threatened the poor man with physical violence if he did not stop making noise so they could sleep. The next morning he was dead. In all liklihood he was buried in one of those graves whose only marking is a patient number. While the physician-patient ratio at Bryce was then and now is inadequate for even a pretension of meaningful psychiatric treatment of patients on an individual basis, the ratio was nevertheless substantially in excess of the physician-population ratio in the society as a whole. There would appear to be little excuse for the staff's not providing medical attention for physical illnesses of the patients on the weekends.

ITEM 8 - The hospital staff should be ordered to cease forcing persons who are physically ill and weak to work.

On one occasion while the writer was working six days a week in the magazine sorting and storage room attached to the patient library, he became ill with a disease resembling either mononucleosis, hepatitis without jaundice, or a cytomegalovirus (all three have similar symptoms). An exact diagnosis was never made although some laboratory tests were performed. He suffered spells of extreme physical weakness and intermittant fevers. He pretended to his physician to be less ill than he really was so he could continue to go to the library storage room daily. During the six week period in which this disease was acute he was compelled by circumstance to lay on a hard table in this room all day long each day from Monday through Saturday, arising only during the partial relentment of his weakness to sort and shelve magazines which occasionally were brought into the room by other patient-workers. The reason all this was necessary was to avoid an autocratic, cruel attendant on his ward who ordered the patients about every day mopping, waxing and polishing the floors. He was able to avoid this attendant Monday through Saturday and, being a trusty, avoided him on Sunday afternoons by lying on the ground under the trees on the front lawn. On Sunday morning, however, the writer had to lie on his bed on the ward as no one was allowed out then. One Sunday morning the attendant forced the writer out of bed to mop the floors. A request for exemption on the grounds that the writer was physically weak was to no avail. On subsequent Sunday mornings the writer avoided this attendant by hiding under laundry bags in an isolated area of the grill-enclosed porch of an adjacent ward.

-5- of 7

ITEM 9 - The practice of imposing involuntary servitude on patients at the state mental institutions should be ordered stopped. Additional examples of this allegedly occurred in connection with the hospital farm at Bryce. A fellow patient who had been there for a number of years told the writer that he had been ordered in a very compulsory manner to do hard manual labor on the farm and that others of his fellow patients had been likewise ordered to do so. He said none of them would have dared to resist obeying the instructions. Two other patients the writer knew, one of which had been at Bryce since the Titanic sunk prior to World War I, worked as painters. They worked regularly eight hours a day and forty hours a week. They could have worked just as well on the outside. Their remmeration: substandard room and board and eight dollars a week.

ITEM 10 - The hospital officials should be ordered to cease compelling patients to deposit all of their cash money in a hospital custodial fund in return for which they are issued coupon trading books. A minimum amount of cash--say ten or fifteen dollars--should [illegible] the average patient's right to keep at all times. The argument that trouble could more likely arise on a ward from money being stolen is invalid as coupon books are just as easily stolen. While the writer was there the stealing of a coupon book was almost unheard of.

In 1962-63 the hospital allegedly staff's procedure with incoming mail was to open it in the presence of the patients, and while they did not read the incoming letters (as they did the outgoing letters), the cash was removed from them nevertheless. Not having cash money made it very difficult for a patient to escape the horrible hospital conditions by running away and thus helped minimize patient turnover. A low turnover contributes to the maintenance of the deplorable human situation that exists in the Alabama state mental institutions.

ITEM 11 - An investigation of all miscellaneous operating procedures at the mental institutions should be made and orders issued for the cessation of any improper practices which may be found. A patient who worked at the employee cafeteria at Bryce told the writer that government surplus powdered milk marked "not to be sold or exchanged" was mixed half-and-half with whole milk from the hospital dairy prior to being sold to the attendants.

ITEM 12 - Practices such as the following should be ordered to cease and the order effectively enforced: Prior to the writer's being administered an electroshock "treatment"--more properly termed mistreatment--a doctor of medicine would administer a shot which paralyzed the entire body, including involuntary breathing muscles. After the electrodes are placed on the temples and electric current begins penetrating the victim's brain, his body shakes violently with convulsions so intense that there is danger of his arm or leg bones being broken. The purpose behind administering the paralyzing substance, of course, is to reduce the intensity of body convulsions. The called curare.

substance described is a diluted form of/a poison used on arrowheads by Indians in the jungles of South America. Being injected with this stuff while still conscious is horrible beyond description. The victim feels himself sinking into helplessness and becoming unable to breathe. He can feel indescribably unpleasant spasms in his internal body muscles--including his lungs--as this process takes place. It would seem only reasonable and humane that a person be given an anesthetic to produce unconsciousness before any such alien substance were injected. Not so at Bryce. Only one of eight "treatments" imposed on the writer was preceded by an anesthetic. Seven had to be endured by the torture method. They stopped administering the shocks only because his mother specifically instructed them to do so by letter.

ITEM 13 - Punitive practices such as the following should be ordered to cease followed by effective enforcement: The terrible experiences described in Item 12 above produced ever increasing fear of each electroshock which exceeded fear of the previous one. Eventually the fear became intolerable and the writer told his medical doctor he could not stand any more of them. She assured him they would not be stopped and ordered him placed on another ward. On this new ward he was locked inside all day long and not allowed the freedom of being herded with other men like cows onto and off of an open yard an hour or so every day as he was privileged to do on the ward from which he was moved. At nights he was locked into an individual cell to sleep on the floor. Not the slightest dissent dare be expressed at any of these things.

ITEM 14 - The appropriate state agency that has jurisdiction for auditing the state mental institution records should do so at the earliest possible time. This should be given an urgent priority.

All reform destined to be effected at Bryce and Searcy Hospitals in the near future notwithstanding, these institutions will still remain custodial rather than therapeutic. The massive funding necessary to set up a decent therapeutic program for each individual patient obviously is unobtainable. Unfortunate persons who are chronically afflicted to such an extent that they cannot recover and function without constant assistance obviously need to be cared for. The important thing is that their custodial care be as humane as possible and that it ease the terrible woes that are upon them instead--of all things--of worsening them. A stepped-up "therapeutic" mistreatment program should not be allowed to begin in the name of broadening the availability of individual treatment in these abominable institutions. All new programs should be judged by the most rigid criteria of quality to make sure they are not of the type described. Shock treatments should be allowed to be administered only by properly trained and dedicated people under the proper circumstances. The book entitled The Mentally Disabled and the Law says of electroshock therapy (again on page 149): "The Council of State Governments reported that 'although its mode of action is unknown there is much evidence to suggest its usefulness in a great number of the present mental illnesses.' However, the study emphasized that no reputable psychiatrist would recommend its use without careful preparation and follow up. IT IS QUESTIONABLE WHETHER UNDERSTAFFED STATE HOSPITALS COULD CARRY OUT THE PREPARATION AND FOLLOW-UP RECOMMENDED."

The writer would like to point out in closing that of those Bryce patients among whom he circulated, fully 80% of them were chronic alcoholics who were absolutely normal in the hospital after they were forced by confinement to abstain from alcoholic beverages. The other 20% were mostly epilectics and juveniles (some of the teen-agers were from reform schools but many were not). A large percentage of those patients on wards other than where the writer was assigned are geriatric nursing-home type patients whose families receive free state-paid custody of their relatives while other Alabamians are having to pay for their nursing home services.

Contrary to the opinion of certain persons in the public very few were emotionally disturbed to the point that they were seriously out of contact with reality or "crazy." Neither are they ravenously dangerous as some people conceive of them. Considering the ordeals they have to endure they are remarkably placid. In fact, they are to be commended for their endurance of injustice. Since the vast majority of these people are not insane by the definition of the law (it requires a trial by jury to declare a person legally insane and these persons do not get such a trial), their testimony is just as legal as the testimony of someone not in the hospital. These people constitute a vast reservoir of testimony as to what goes on inside these hospitals. If they see that "London bridge is falling down" and they will be safe from any reprisals, thousands of patients and former patients are now in a position to testify. Why not utilize some of this vast reservoir.

If I can be of further service you may contact me by mail or by phone at 996-5678. With best wishes, I am,

Very truly yours,

James E. Wamble, Jr.

James E. Wamble, Jr.

BEST COPY AVAILABLE

April 4, 1985

Dear Sen. Weicker,

I would like for my letter to become part of the testimony for the Senate Sub-Committee for the Handicapped.

My 23 year old daughter, Dianne is a resident of the Ft. Worth State School, that has been her home for 8 years, prior to that she lived in the Corpus Christi State School for 6 years. Dianne is brain damaged, I had surgery before she was born. She is profoundly retarded, cerebral palsy, visual impairment, hyperactive, seizure disorder, ambulatory and medically fragile. She is normal size and has a mental age of 16 months. Dianne started school at age 2½ and lived at home until she was nearly 10. We looked at many places for her and decided that the state school was the most appropriate, least restrictive and could give her the protective care she will need for as long as she lives and I feel the decision was right then and still is. She has been well cared for, is probably the happiest person you've ever seen and has the companionship of friends that she can relate too. I have a daughter who is a very successful attorney in Austin, Tex. and another daughter who is an accountant for a large construction firm in Austin, Tex. My husband, daughters and myself love Dianne, we take her on trips and have her home often and for all holidays, we have accepted her limitations and enjoy every minute we spend with her. But Dianne must have the constant 24-hour supervision that only the Ft. Worth State School can give her, she will wander outside day or night if she can get the door open and goes immediately into the street with no fear of the cars, she is also non-verbal so she would not be able to tell anyone her name if she got lost. She would be unsafe in a community group home that is being pushed for all mentally retarded persons by certain advocacy groups. I am also opposed to the private provider because they are profit-oriented not client-oriented.

The testimony presented to your committee by two parents of children at the Ft. Worth State School and the media coverage has been hurtful to many parents and staff alike. I am President of the Parent Assoc. and have [illegible] many parents who feel the school is doing a good job and [illegible] disagree with Mr. [illegible]ridge and Mr. Cockerham. The school is [illegible] void and filthy and I invite you to come unannounced for a tour and see for yourself. Mr. Savidge, under oath, testified in Judge David Schoch's on Nov. 2[illegible], [illegible] that Jonathan while living in his loving home environment was tied to the kitchen table to keep him in one place or he was in a playpen. I am very sorry that Jonathon was ill and required surgery, but I question why his father did not take him for a second opinion if he was not satisfied with the school's opinion and treatment. I have done this many times for my retarded daughter, because I would do this for myself or any member of my family. With the opinion Mr Savidge has of the school and as he says the total failure of care for Jonathan, it is hard to believe that he would leave him there one day. The parents feel very badly about the injury that Chris Cockerham received and asked the Suptd. to set very rules on any suspected abuse cases because we do not want this to ever happen again to any client. We do feel that the fact they have a 14 and 20 million dollar lawsuit against the school, handled by David Ferleger, a Philadelphia lawyer would make it difficult for them say anything good about our school.

I am a volunteer at the school, therefore I spend a lot of time there, also I know most of the staff members and feel the Supt. and his entire staff are caring, dedicated and interested in our children. The work is hard, stressful, lowpaying and we do need more staff than the ICFMR mandates because our children require total care and many are so helpless.

I hope that the hearings will help us in some way, but I do wish we could have had a more balanced view of Ft. Worth State School since the majority of our parents know and love the school and want our children to stay there because they are so happy and satisfied. The Parent Assoc. has many projects to improve the quality of care for our children. We have flea market sales, bake sales, parties and help the school in many ways. Many parents donate large sums of money to Volunteer Services for items needed by the school. We have a lovely indoor heated therapy swimming pool donated by the community and foundations in Ft. Worth.

Since you are the parent of a retarded child you can understand our feelings and fears of what will happen to our children when we are gone or unable to care for them, we feel secure that they will be cared for in the state school. I hope that you and your staff will plan a visit to our school and I would look forward to meeting you. Thank You.

Sincerely,

Nancy Ward
4526 Harley Ave.
Ft. Worth, Tx. 76107
817 [illegible]

April 2, 1985

APR [illegible] 1985

Senator Lowell Weicker
Subcommittee on Handicapped
Senate Office Building
113 Hart Street
Washington, D. C. 20510

Dear Senator Weicker:

I am a satisfied parent whose daughter resides in a State School in Texas, and I want my letter to become part of public testimony which favors State Schools for the Mentally Retarded.

The parents in Texas who filed class-action suits against the State Schools can only speak for their sons and daughters. What happened to their sons and/or daughters does not apply to my daughter, who has blossomed in the state school environment of which she has been a part for 20 years. My daughter is safe and happy there and that makes me happy. I realize good news does not make headlines and that only negatively bad and sensational news gets the attention of the news media. Surely you realize that for every parent who is unhappy about State Schools for the Mentally Retarded, there are 50 parents who favor this environment for their family members. By the way, the word "institution" denotes a negative connotation used by the parents who filed the class action suits. I refuse to use the word, even though it is not a "dirty" word, per se.

While conducting your Senate hearings, should you ever want to publicize success stories about the mentally handicapped and the excellent services they receive at Denton State School in Texas, please use my name and my personal testimony as a public reference. My testimony will be valid and accurate and will reflect a needed positive opinion.

Thank you for your consideration regarding my concern.

Cordially,

Mrs. Robert T. Magill

Mrs. Robert T. (Minnelle) Magill

Testimony Regarding
HEARINGS ON THE CARE AND ADVOCACY OF MENTALLY DISABLED PERSONS IN INSTITUTITONS

Before the
LABOR AND HUMAN RESOURCES
HANDICAPPED SUBCOMMITTEE
April 1985

Presented by

Kaye Barthuly
1025 N. Parkwood
Wichita, Kansas 67208

Mr. Chairman and distinguished members of the Handicapped Subcommittee:

I am Kaye Barthuly, a Licensed Baccaulaureate Social Worker in the State of Kansas.

I thank you for the opportunity to express my views on the care of mentally impaired individuals in intermediate care facilities (ICFs). Due to the large numbers of mentally impaired individuals in Kansas nursing homes, I believe their care or lack of it is an important issue. There are two reasons for the large numbers; the deinstitutionalization movement which transferred the mentally ill from mental institutions to intermediate care facilities and the lack of space in ICFs designated for the mentally ill.

As a social worker who has been involved in the care of mentally imparied residents in intermediate care facilities, I would like to support the concept of nursing homes and mental health centers working together on resients mental health needs. I am in favor of Medicaid reimbursement for mental health coverage within intermediate care facilities, which would enable them to better serve their mentally impaired population.

I support the idea of coordinated services between nursing homes and mental centers for two reasons:

1) There are many mentally impaired individuals in ICFs in need of mental health care.

2) Nursing home staff are not adequately trained in the area of mental health and cannot properly care for mentally impaired individuals.

There are two major reasons for mentally impaired individuals residing in intermedite care facilities in Kansas. First, the deinstitutionalization movement frequently caused the displacement of mentally impaired individuals from mental institutions to intermediate care facilities. Second, the State of Kansas designates separate intermediate care facilities for the mentally ill, called ICF-IMDs(Institutions for Mental Diseases). However, many mentally disabled individuals reside in intermediate care facilities due to limited space, cost or distance from an ICF-IMD.

Nursing home staff are taught about the basic care of the geriatric resident and have little training about the needs of the mentally impaired individual. In addition, intermittent mental health in-service trainings do not reach all staff since turnover of staff is high in nursing homes.

I propose that nursing homes and mental health centers coordinate efforts to maximize the special care that mentally impaired residents require. This model of coordinated services is presently available in the Kansas four county area of Sedgwick, Harvey, Marion and McPherson to area ICFs through Prairie View Mental Health Services of Newton, Kansas.

In this model, mentally impaired individuals receive specialized services, such as in house individual and group therapy, screening and evaluations by Prairie View staff. The Prairie View staff also provide on-going consultative services to the nursing home staff on individual patient's treatment as well as offer intensive continuing education for all staff on the proper care that mentally impaired residents need.

I would like to cite two examples of residents residing in intermediate care facilities that could have benefitted from coordinated services with a mental health center. The real names of the individuals have been changed to protect confidentiality.

Case Example 1

Carol, a woman in her mid 50's had been deinstitutionalized from a mental institution. Due to her family being unable to care for her at home, Carol was admitted to an intermediate care facility. She was diagnosed as having schizophrenia and chronic depression. Carol noticed that she was "different" from what she referred to as the "old" residents and she regarded them with suspicion. Carol had severe mood swings and would become extremely angry with her roommate, who was in her 80's, and request a room change one day and express contentment the next.

Carol seemed in need of extended therapy, possibly with a group her age. If Carol could of been linked with a mental health center, she may have become better adjusted to her living situation plus staff could of learned how to cope with Carol's mood swings.

Case Example 2

Laura is a woman in her late 80's who had no prior record of mental impairment before entering the nursing home. Laura had no family except for a distant relative in another state. Laura was extremely depressed most of the time, often not getting out of bed for days. Laura frequently talked of wanting to die and how the staff and other residents hated her. Laura attended very few facility activities and would often cry when approached by staff. Laura's problems were usually treated with medication, often she was over-medicated. Laura, like Carol, was in need of therapy from a professional in the mental health services. Limited staff training and lack of staff time did not allow Laura to be treated properly or with the dignity she so desperately needed.

Although these two case examples have different backgrounds and reasons for being in the nursing home, they share the common denominator of mental impairment. These examples illustrate that there are mentally impaired individuals in intermediate care facilities whose needs are going untreated. Since mentally impaired residents are rarely given the opportunity to advocate for themselves, I would like to for them. I advocate in favor of Medicaid reimbursement of mental health coverage within nursing homes. This reimbursement policy would encourage intermediate care facilities to coordinate services with mental health centers, like in the Prairie View model, for their mentally impaired residents.

Thank you.

[illegible] Federal Building
[illegible] Walnut Street
Des Moines, Iowa [illegible]
[illegible]

[illegible] Federal Building
[illegible] 1st Street S.E.
Cedar Rapids, Iowa [illegible]
[illegible]

United States Senate
CHARLES E. GRASSLEY
135 Hart Senate Office Building
Washington, D.C. 20510
(202) 224-3744

[illegible] Street
Sioux City, Iowa [illegible]
[illegible]

[illegible] Waterloo Building
[illegible] Commercial Street
Waterloo, Iowa [illegible]
[illegible]

April 15, 1985

Senator Lowell Weicker
Chairman
Subcommittee on the Handicapped
SH - 113

Dear Senator Weicker:

Enclosed please find a letter and statement sent to me by one of my constituents who asked that I forward it to your committee to be included as testimony in your recent committee hearing.

With kindest regards,

Sincerely,

Chuck

CHARLES E. GRASSLEY
U. S. Senator

CEG:bb

Will you please – send to my constituent – that you rec'd it!

TERRENCE J. and JUDITH REISDORF
3275 GETTY TERRACE
DUBUQUE, IOWA 52001
(319)556-3754

April 9, 1985

The Honorable Charles E. Grassley
Member of U.S. Senate
232 Russell Senate Office Building
Washington, D.C. 20510

Dear Senator Grassley:

Last week there appeared a story in our local paper on hearings being held by a Senate Subcommittee on the issue of treatment of the elderly and mentally ill that are in or confined to Mental Hospitals. Also, We've watched some of the proceedings on C-Span. I made note that the Chairperson made the remark that the Subcommitte was keeping the record open for anyohe wishing to make written statement to the Committee. These hearings may result, in an indirect way to better quality care to persons like myself, with less "red tape" on admissions and lengths of stays involving the medical needs to persons that suffer mental illness, like myself.

My wife and I would like it made known to those holding these hearings the problems that I have run up against while trying to gain such care. We are sure that there are thousands of other patients experencing the same problems since the start of DRG's. Just as there were thousands of us unjustly removed from the Social Security Disability Rolls in 1981-1982 only to be reinstated after hearings before ALJ's. If my case can be entered into the record of the hearings now being held, and if it may help others to gain the medical treatment they so greatly need, we urge you, Senator Grassley, to present the folowing pages to the Subcommittee on our behalf.

Sincerely,

Terrence J. and Judith Reisdorf

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I was awarded Social Security disability benefits in 1973 for the reasons of mental illness. My claim for DI was submitted to our State DDS by my wife on the advice of my attending physicans. I was confined to the State Mental Health Insititude at that time.

Prior to that time I was gainfully employed for a period of 11 years. However from 1967 to 1973 I was admitted many times over for the treatment of my impairment. In 1973 when I was granted DI it was felt by the State DDS that my condition may improve, therefore my case was to be reviewed in 1974. I came under periodic review in 1975 and was found to still be disabled. In 1981 I again came under review by DDS, in fact I was hospitalized at the time of the notice of review. In September of 1981 DDS made the decision that I was no longer disabled and my benefits were denied at the Reconsideration level.

With the assistance of Congressman Tom Tauke and his caseworker, Carole Snodgrass, my wife and family were sucessful in gaining medical evidence to present to an ALJ at a hearing held in March 1982. At that hearing the judge told us that there was no doubt in his mind about my not being able to any longer do substancial gainful activity because of the limitations placed on me because of my impairment. In an "off the record" remark the judge urged me to stay in treatment, to be admitted to hospitals when needed, and to always remain on medications.

Today however, it has become very hard to gain the treatment as an inpatient that I and others like me need to be able to function what is considered normal by physicans, because of DRG's and PRO's. In past years treatment for me would involve a hospital stay of 4 to 10 weeks. Today such persons like myself are being discharged after 1 to 2 weeks. We are being "forced" back to our homes in "chemical straight jackets" due to the chemotherapy being used.

We are no longer given the benefit of a period of hospitalization to make sure that the changes in our chemotherapy will be of value to us. The ALJ noted in his written decision, based on the many hospital and clincal records presented to him by physicans, of the many different types of medications that I've taken, being of short term, or little value to me in the treatment of my disorder.

Although I have somewhat been able to accept the reality of my limitations because of my illness, I will never be able to understand the illness itself. Congressman Tom Tauke wrote along those lines in a letter to the ALJ dated March 5, 1982. In part he stated:

> "Dr. R.H. Lee has been his psychiatrist since October, 1967. Dr. Lee has assisted Mr. Reisdorf to accept the reality of his limitations. It has been difficult for Mr. Reisdorf to admit to himself, his family, and his friends that he does in fact have to restrict his

> activities because of his disorders. — He is not able to undergo the stress that is caused by substantial gainful employment."

In a statement given before The Select Committee On Aging on June 28, 1983 during hearings on the issues of "The Disability Program and Disability Review," Congressman Tauke again made mention of me to the Committee when he states in part:

> "Or I think of another constituent who was initiall granted Disability benefits because of severe mental illness. He was reviewed and terminated from the rolls, then, after months of severe anxiety, reinstated at the ALJ level. He has periods of mental health in which he would very much like to volunteer his services in the community. He is bright, articulate, capable during these periods. Yet he fears volunteer work. He is haunted by the spectre of another review, and he worries constantly about the state of his "file." Are his records complete?"

Although Congressman Tauke speaks of not being able to cope with the stress of employment, my medical history proves this to be fact in every day to day normal situations. Again, although I do not understand my illness, or understand about "chemical imbalance, bi-polar disorders, manic-depression, etc.," I do know only to well that because of these disorders I cannot function the way "I think I should."

On one hand only I really know when I again must return to a hospital because medication that I am on is no longer working. I fear seeking such hospital care because of no longer being allowed the stay that had always been needed in past years. I, as others like me, cannot cope with todays merry-go-round called DRG's. In the past few years if it were not for the concern and assistance of Congressman Tauke's caseworker, I would never have been allowed the length of hospital days that are needed for my care. Because of such assistance my hospital stays have not been as beneficial as past years when I and others have to "fight" Utilization Review Committees for every hospital day. We are finding ourselves being discharged before we (and often our physicans) believe we should be. Since the DRG's we are being "thrown out" because of cost-based reimbursement to providers.

Some years ago a physican remarked about how I came a long way in the acceptence of my disability. Today I and others like me are back to "square one." In my most recent hospital stays (1984) nurses and physicans agree on one thing about todays medical treatment for mental illness, and that is, it is wrong. One physican told my wife that "when someone from Utilization Review, reviews a patients chart and reads that a patient is sleeping, eating and smiling. The patient will be ordered to be discharged."

I have seen to many patients prematurely discharged from the Mental Health Unit only to be readmitted to the unit within a day or two after making an attempt at suicide. Some will never return to their homes and families. In one such case I heard a physican remark about a suicide, "win a few - lose a few." Like me, many patients are still very disorganized in their thinking on being discharged, be it from their illness or medication side effects. I seen one man stand for over three hours by the nursing station because he just plain didn't know what to do or where to go upon his discharge. A nurse (caring?) told him he would have to leave the unit because he was no longer a patient. I watched the man cry and beg to be allowed to stay. I also watched as the hospital security escorted him off the unit. He was readmitted through the city police that same night, he was again discharged a few days later.

I am again to the point in my illness that hospitalization is needed, this has been true since November, 1984. Yet I refuse to admit myself. In past years I had done the same but not because of the reasons I write about today. In those past years I was eventually committed by my family and once by the court because of "a serious attempt at suicide," (which I don't remember). In these past months I've had many sleepless nights, it takes me ten times longer to do the most simplest of chores. My wife is forced to drive herself to work each day, and I know she along with my children fear for my well being. I stay in my home most every day because right now I can't even do such things as going to the store without becoming disorganized.

These writings have taken me at least 72 hours to write because of my illness. Even though I have a word processor and an I.Q. of 148 my disorders won't allow me to function at the speed I want. Since my reinstatement to SSDI in 1982 I have developed heart problems. Because of COLA's and my wife's earnings our monthly rent under Section 8 HUD Housing is $683.00 a month. Therefore we are being forced to move into less expensive housing. Although an ALJ overturned my DI termination in 1982 and I have Medicare and other private health insurance, I, and others like me are not being allowed the medical care we need. It is as if that in making the decision the ALJ made in our cases the SSA is saying! "We are aware that you are disabled under administrative law and as such we agree to send you a benefit check each and every month as long as you agree not to do anything but stare at four walls everyday. Don't seek hospital care for your disorder because it is way to costly and it cost to much to review your case each and everytime you go into a hospital. After all, you are not truly sick, just crazy and we, the SSA through the DDS, again plan to cure you someday again with a letter. Of course if in the meantime you should get a bullet in your head and no longer "play our silly game, we just may admit that maybe you were sick and disabled."

Testimony Regarding

HEARINGS ON THE CARE AND ADVOCACY FOR MENTALLY DISABLED PERSONS IN INSTITUTIONS

Before the
LABOR AND HUMAN RESOURCES
HANDICAPPED SUBCOMMITTEE
APRIL 1985

Presented by
Marti P. Fritz

1010 Litchfield
Wichita, Kansas 67203
Telephone (316) 265-9964

Statement of Marti P. Fritz, Wichita, Kansas

Mr. Chairman and distinguished members of the Subcommittee on the handicaped: I am Marti P. Fritz, a graduate student in gerontology at Wichita State University, Wichita, Kansas. I would like to thank you for the opportunity to express my views concerning the landmark hearings on state institutions for mentally disabled persons. By mentally disabled, I am referring to both, the mentally ill and the retarded.

Legislative Proposal for a Citizen Advocacy Program

As a concerned citizen for the institutionalized elderly, I urge that you support the passage of legislation which will establish a comprehensive citizen advocacy program. An act similar to the Mental Health Systems Act (Public Law 96-368) needs to be enacted. Rather than appropriating federal funds to state advocates for the mentally disabled, I propose that the funds be allocated to the National Association for Retarded Citizens (NARC). They would in turn allocate the funds to some non-federal/state operated agency, such as the council of churches or the local or state interfaith coalition. Those agencies funded through NARC will be responsible for developing, implementing and maintaining the citizen advocacy program. It is crucial that the citizen advocacy program is administered by a local agency which is not federally or state operated. This avoids the serious political ramifications that federally funded state advocates for the mentally disabled now face. Many of these advocates were fired from their jobs due to an intra-governmental conflict of interests. These advocates who were hired by the state would file lawsuits against mental institutions owned by the the state; as a result, federal and state monies were being used against the state government's best interest. My proposal avoids these unintended consequences and thus is free from conflicts of interest.

Description of a Citizen Advocacy Program

I propose a citizen advocacy program which adopts many of its ideas from Diana Fricke, who established a successful advocacy program in Fort Worth, Texas, in 1982. Citizen advocacy is clearly a program to be implemented at the local level. The local agencies who receive funding from NARC are responsible for hiring an advocacy coordinator. The coordinator is responsible for recruiting and training volunteers as citizen advocates. A citizen advocate is a mature, competent volunteer representing, as if they were his own, the interests of another citizen who is impaired in his instrumental competency, or who has major expressive needs which are unmet and which are likely to remain unmet without special intervention. The volunteer, in this particular case, advocates for mentally disabled older persons, who live in state mental institutions. The citizen advocate performs many different duties, such as interpreting the Patient's Bill of Rights to incoming mental patients, including the daily review of the patient's chart and interpretation of the chart to the patient; assist the patient's family in understanding the nature of care and treatment being received; spend time with the patient on a personal bases, to determine his or her well-being and comfort; and receive complaints from patients and their families concerning institutional abuse and report this to the coordinator. These are important functions that a citizen advocacy program must address.

Case Studies

The following case studies of the mentally disabled are examples which illustrate how citizen advocacy can make a difference in their lives.

Case Narrative No. 1

Joe, a citizen advocate who was one of Diana Fricke's volunteers (Diana is currently a citizen advocacy coordinator for the ARC-Fort Worth, texas) was told that the man he was matched with would have to move through the continuum....from training center to sheltered workshop to work activity center...before he could be competitively employed. At this point, George was in the training center and had been for a number of years, apparently, he did not live in a mental institution. Joe thought there had to be a quicker way. He found a local employer who agreed to give George a chance, then enlisted the aid of a friend who had been a Marc Gold trainer to help George and those who would be working with him. Two years later, George is still employed at the same job. Joe did not accept the absolute need for the continuum. Due to citizen advocacy, George was able to find employment more quickly and thus become more independent.

Where are the advocates for the mentally disabled who live in institutions? There are no examples that I know of where citizen advocates are helping the institutionalized adult find employment. This special population continues to be neglected and the price paid for this neglect is in the loss of human potential and human dignity.

Case Narrative No. 2

My sister, Becky, who was a former patient at a state mental institution was exposed to many abuses. Becky was sexually harassed by one of her doctors. Sexual harassment included, such gestures as patting her on the butt and kissing her on the lips. Becky immediately reported this incidence to the administrator and requested to be transferred to a different doctor. No corrective action was taken. Another problem centered around

Becky's psychiatrist, who was in charge of monitoring her medications. The doctor was from South Korea and could not fluently speak nor comprehend the English language. For example, my mother who periodically consulted with him had to write her messages down in order for him to fully comprehend the message. Again, no corrective action was taken when my mother requested to have Becky transferred to an English speaking doctor. In desperation, my mother reported it to Becky's social worker who simply disregarded the complaint.

This story is like the thousands of other mental patients who have no place to go to find help. If my sister had a citizen advocate to act on her behalf, changes could be made. The advocate has the power to pressure the institution into changing its practices by reporting it to the newspaper or by taking legal action. In conclusion, both these case studies demonstrate that citizen advocacy for the institutionalized mentally disabled is a useful strategy which is badly needed.

Supporting Evidence

I support the citizen advocacy program for several reasons. The first reason is because there are more mentally disabled patients living in institutions who are reaching old age. They are living longer and thus increasing in their numbers. Various research studies support these facts. In a retrospective study of a group of mental institutions in England (Carter and Jancar, 1983) conducted during the years of 1936-1940 found the average age of a male patient to be 15.7 and female patients 26.3. By 1976-80, the average age of a male patient increased 58.3 percent and for females 59.8 percent. Similar reports on this general trend towards increased longevity can be found in McCurley, et al., in Ireland, and Tarjan, et al., in the United States (1968). I conclude from these statistics that citizen advocacy is badly needed for this special population and Congress should address these issues. The second reason for supporting citizen advocacy is because many of the mentally disabled outlive their natural advocates, their parents and thus have no one to advocate on their behalf. The last reason for supporting this measure is because volunteers may end up doing much more than advocacy. They may go as far as becoming guardians, foster parents, and even adopting parents.

Advocacy Reform

The success of citizen advocacy is dependent upon several factors. Legislation needs to be enacted which guarantee the right of a citizen advocate to visit a mental patient at any time and have access to a patient's records. Under the preexisting laws an advocate does not have these privileges and, therefore, is unable to perform his or her job effectively. For wards of the state, legislation should be enacted, permitting parents, guardians, and advocates to remove the patient from the state institution for the purpose of having a physical examination to varify the extent of injury caused by the suspected abuse. And finally, protective laws should be legislated which protects the employee from jeopardy (i.e., being demoted or losing their jobs) whenever they report institutional abuses. I urge that you support such legislation--to keep the laws as they are will make it virtually impossible for the citizen advocate to eradicate institutional abuse.

Summary

Citizen advocacy needs to be implenented at the local level. The special needs of the mentally disabled institutionalized adult must be addressed by Congress. Advocates are needed to act on their behalf. The citizen advocacy program I have proposed can be a powerful force. It can make a difference, but only if we believe in it, understand it and support it. Mr Chairman and distinguished members, I urge your support for legislation governing these matters.

Thank you for your consideration.

PAUL SIMON
ILLINOIS

United States Senate
WASHINGTON, DC 20510

April 25, 1985

Honorable Lowell Weicker, Chairman
Subcommittee on the Handicapped
Room 113, Hart Senate Office Bldg.
Washington, D.C. 20510

Dear Mr. Chairman:

Enclosed is a copy of the testimony I received discussing conditions in an institution for the mentally ill in Rockford, Illinois. I would appreciate your including it in the hearing record for the Subcommittee hearings on institutional abuse.

For the information of the Subcommittee, Ms. Kobler's address is 2011 Oxford, Rockville, Illinois, 61103. She would appreciate, however, having her address omitted from the hearing record.

Thank you for your assistance.

Sincerely,

Paul Simon
U. S. Senator

PS/sp

Enclosure

I am a registered nurse and have been employed by the Department of Mental Health for the past 12 years at Singer Mental Health Center, Rockford, Illinois.

I have always taken great pride in both the facility and the fine direct care staff serving there. We have accomplished so many wonderful things for our patients in the past; I only hope to augment the quality of patient care in the future. This concern is the purpose of my correspondence and written testimony to you. I desperately need your assistance.

I have been viewing the Federal investigations and Senatorial hearings regarding mental health with great interest. So much of what was said seemed to tell Singers' story. However; I noted that none of those who testified were direct care staff. I felt that you needed testimony from such a person as myself; a professional who delivers the patient care and shares the same concerns as others who testified. Perhaps my eye view account of the effect of bureaucratic dogma, lack of concern and refusal to make essential changes will assist in your investigation. Please understand that this is not my first attempt at being heard regarding my concerns. I have spent the past several months in numerous meetings with Mr. Donald Hart, Department of Mental Health Regional Director; Dr. Matthew Parrish, Superintendent, Singer Mental Health Center; Zeke Giorgi and John Hallock, State Representatives; Senator Joyce Holmberg and am still waiting for a response from Congresswoman Lynn Martin. Residually I have seen no investigation, nor any effective change in the conditions at the Singer facility. For this reason I turn to you and offer you this testimonial at some personal risk.

1. In September, 1984, I discovered that management was not only working overtime hours themselves, but at times were actually creating it. This came at a time when direct care staff were told that staffing would be minimal on the units and that there would be no overtime. I filed a complaint and in the interim, I suffered bricks though my car window, several phone calls threatening the lives of my three children and finally, a fire which destroyed my childrens playhouse. The fire was ruled arson. The States Attorney, the arson squad and the detective bureau were all involved and administration at Singer Mental Health Center assured me there would be an internal investigation. Yet, even after proving the complaint and manifesting corruptive overtime practices committed by management, no investigation occurred nor where any of the management penalized in any way. It was implied by administration that they would give a list of names to the detectives, but later, administration felt the harassment would continue if the case was not closed.

2. Mr. Donald Hart, DMH Regional Director, agreed that the terrorism at my home pointed to Singer management. This occurred during a meeting with Representative Zeke Giorgi, Mr. Hart, Mrs. Vicki Fulton, RN, and myself. Despite this no investigation or cooperation with local authorities occurred.

3. In the recent past a mandate came from Springfield to delete several regional positions. Instead, regional Administration

transferred positions onto Singer payrolls and laid off Singer outcare staff. Outcare workers are Singer staff who not only maintain existing placements for patients in the community but also secure new placements. These staff members were responsible to DD and geriatric placementients in the community. We now no longer have an outcare team and our census continues to rise. Instead, we have maintained regional positions on Singer payroll that in no way contribute to patient care or placements.

4. Since the closing of Dixon Development Center and their merge with Singer Mental Health Center, policy and standards inferior to our past standards have been imposed on the units housing emotionally ill patients. This reduces the quality of care delivered to our patients. As you well know, developmentally disabled differ greatly from emotionally ill patients. This should not only be recognized but defined and observed. Many of the DD units function under nursing home standards, requiring only four hours of a Registered nurses time weekly. Mentally Ill units fall under a strict legal and medical umbrella. Our units require a Registered nurse 24 hours per day per 30 beds or a Registered nurse and 2 Licensed Practical nurses per 60 beds. We fear that during a gradual process in the coexistance of MI and DD, nursing standards and care will be greatly altered and reduced.

5. In addition a Registered nurse was appointed Director of Nurses who had no experience at all with direct nursing care nor any level of skill with either DD or MI patients. Nursing staff questioned her appointment and her credentials. We asked how a woman with no

active nursing experience in either specialty could be appointed to Director of Nursing. Management agreed that perhaps she was the wrong choice, however she continues to be director of nurses as I write. Although she worked for many years training DD technicians, at the Dixon Developmental Center, she spent no amount of time in direct care of those same patients. She openly admits knowing nothing of psychiatric patients and yet to date has made no attempt to visit the MI units or spend any time with these patients. She has maintained this position for the past six months.

6. Medical Services is the clinical medical setting at Singer where patients are taken for specific medical procedures. This assures the patient quality medical care in a clean safe environment. The new Director of Nurses and the Superintendent arbitrarily decided they would close the entire service. The entire facility was in an uproar over the closing of Medical Services and the rationale for closure was never offered. As a result, the patient falls to the bottom of the bueracratic strata and relinquishes quality services once more. Staff suffers as well in the addition of physicals and medical histories to their work load. Dr. Modir, the clinical administrator for Adult Psychiatric Services battled the closure of medical services all to no avail. The department will close June 1st.

7. One and one-half months ago, a Licensed Practical Nurse (with a previous psychiatric history but hired anyway) became violent on the 11 to 7 shift and pulled a knife and threatened to harm two other staff members. A few days later, she became totally

desperate and barricaded herself in her home, keeping hostage her four year old grandson - it was necessary for the police to remove her and take her to a psychiatric facility. Despite protests from other staff members, she was reinstated and is now working again. The woman is dangerous and jeopardizes both patients and staff. No administration intervention has occurred.

8. Administration is unaware of many concerns at Singer, primarily due to the fact that they spend no time on the units. When approached by front line staff, they listen, ignore and forget. The problems continue with no attempt to change or monitoring of the problems mentioned. Statewide the ratio of administrators to direct care staff is 30 to 100. Singers' administrative staff is 60 to 100!! We have abundant administrative positions yet maintain skeletal staffing on the units.

9. As you have heard in testimony from JCAH surveyors, the facilities are polished and primed before a survey. This is comparable to preparing your home for Christmas guests. The patients and the units are made to look ideal. The surveyors are carefully surrounded by an elite group of management. This allows them to wisk the surveyors through, not allowing them to have any interaction with direct care staff. This is as much the fault of the surveyor as it is administrations.

10. The Director of Nurses is obsessed with cleanliness and rather disinterested with patient care; to the point of assigning cleaning chores to RNs. Two days ago she requested that RN's wear goggles

and rubber gloves while cleaning with caustic cleansers. These are the same hands that change diapers and dress wounds! We have a housekeeping team but she insists the nurses do the scrubbing and mopping. Who takes care of the patients while the nurses mop?

11. Direct care staff scheduling has recently been altered by administration and the result is fewer weekends off and a less than desirable pattern. In effort to reduce overtime, staff is already overworked, and morale has been low for some time. I have pleaded with administration to assign a task force of staff to deal with the problem. My concern is that burnout, low morale and overwork may potentially lead to a series of patient abuse incidences. My plea was offered several weeks ago and as yet I have received no response.

12. A male patient, deemed unfit to stand trial for child molestation, freely rode the city bus one month ago, stopped and bought a switchblade and pulled it on several staff members. It was necessary to call the police to disarm him. Singer insisted on handling this internally and denied staff the right to press charges or even talk to the States Attorney. The patient had no business riding a bus, free in the community in the first place.

13. I have grave concerns also over the screening of potential employees at Singer. In the past administration has hired staff with psychiatric histories themselves. We have dealt with nurses who have histories of drug abuse. Most recently, two staff members were hired from Dixon Developmental Center who were alleged to have

had sexual abuse charges against them in the past. The sexual abuses were alleged to have been committed against against patients.

In conclusion, please know that it is impossible to cite all the examples of Singer's gradual decay. I know that you have the ability and voice to turn it all around. I invite you to visit and hopefully to investigate Singer. Many of our patients are chronic and have lost the support or voice of concerned family members. Patient abuse is not only physical harm - but also the lack of those things necessary to assure him or her the finest care possible and in the healing, an open door to hope and a better future.

Respectfully;
Linda L Keller RN

April 5, 1985

Senator Weicker
Senate Labor & Human Resources
Sub-Committee
113 Hart Office Building
Washington, DC 20510

Dear Senator Weicker:

I sat up very late last night listening to the hearings before your subcommitte on C-Span.

Thank God, someone in high places is at least listening to families of helpless people who must be in an institution; the abuse and neglect of these helpless people is indeed the shame of our nation.

Every complaint voiced by these people I could have made myself about nursing home care. After a year with me, I had to place my mother in the first of 4 nursing homes she has been in the past 9 years. She is suffering from Alzheimers disease which affects a great percentage of our older society, is incurable and renders the patient as an infant after a few years. Mother has been totally helpless for at least 6 years.

During that time, I have witnessed all of the things the families complained about from the State Institutions for mentally retarded. The care, intimidation, secrecy and frustrations in trying to get help all are standard procedure for many (I sincerely think most) nursing homes.

When I heard these sad and frustrated people telling how they tried so desperately to get help when the institutions they trusted failed them, I could feel every pain that they were feeling.

I have seen unwarranted, and many times illegal use of chemical and physical restraints constantly used, or for very long periods of time, and without supervision; brain damaged (senile) patients drugged until they can no longer eat or function, then because they cannot move are left for long, long periods of time with no turning, eventually getting bed sores as large as plates and with the bones exposed (many patients can live for years with these rotting sores). I absolutely thought people with those kinds of body wounds died, but they suffer on for months and I have seen some go into "years."

Falls and injuries are commonplace because of carelessness and hostility. Once an older senile patient is injured (sometimes even slightly) they are almost always tied in a wheel chair, or worse yet, a geriatric chair and left for as long as 12-14 hours a day. Their legs are almost always atrophied in a sitting position.

Once patients are debilitated either by natural causes, or by accidents, they are tied in one position for so long that they become atrophied. Most are atrophied in a sitting position with their legs bent so they no longer fit in a lounge chair or can straighten their legs. Some are in a permanent fetal position from absolutely no movement except for diaper and bed changes. I have never seen therapy given for the prevention of this in a nursing home.

Most are so malnourished, they look as if they were out of a nazi concentration camp. The nursing home always says, "They won't eat." I've never seen one offered food in a reasonable manner who would not eat if given the time unless they were comatose.

Nursing homes are reluctant to give food supplements to the elderly for fear of "prolonging their life." Instead, they prolong their suffering by depriving them of nutrients. The life is still there, and so is the suffering because of malnutrition.

The father who spoke of seeing excrement and urine on the floor while staff sat on their duffs and "worked on paper work" or took their break, or "it wasn't their hall" are everyday occurences in nursing homes.

Elderly people suffer from loss of bone mass and are subject to breakage easily and yet little calcium is given. I have watched aides feed patients and refuse to let them have a swallow of milk until they had eaten all their food. Of course, most have such dry mouths, they cannot salivate enough to chew their food properly without some liquid. At that, only 3 oz. was offered per patient per meal.

Argumentative, provocative and abusive language and behaviour toward the elderly is an every hour occurence. They never know how they are going to be treated from one moment to the next.

When a patient becomes ill, many, many times, a doctor is not called until the person is in death throes. Trying to see the medical charts on a patient is almost impossible. When you finally do get it, you feel that what you might have wanted to see, has been removed, or is so inaccurately reported (sometimes to avoid a lawsuit) it is impossible for someone from the outside to really know what happened. Incomplete, inaccurate and downright false reports in medical charts is a common occurrence.

Dehydration is a continual problem. Most older patients have active bladder infections, because of lack of fluids given, as well as improper cleansing and proper hygiene, and many are never treated for these. It is rare when urine and feces are washed from a patient until time for a bath (usually twice a week).

Aides will withhold fluid and food so they will not have to change diapers and bed, and supervisors do not check.

One of the biggest problems faced is when a loved one in a nursing home is injured and there is no incident report. Most of the "accidents" which occur in a nursing home pass without an incident report being made. When the health department comes out, there is no way they can tell that a person is now confined to a wheelchair or bed for the rest of their suffering life because of the carelessness (and in some cases, deliberate act) of an aide. Few families ever press to find out exactly what happens when an accident occurs as the nursing home always has an explanation. You only "catch on" when you are around long enough to know the patients and observe what really happens to them.

Old and infirm patients are given baths and left in drafts with wet hair. They are left tied in wheelchairs and beds with the heat turned up to 85° in some instances and a cold breeze blowing through their thin clothes on other occasions with aides sitting by not noticing.

Drugs and other unneeded items are charged to the patients bills without family members or care-takers being consulted, ranging from $4.00 to $70.00. Nurses refuse to consult with families on medical care of patients; intimidation by Administrators, Directors of Nursing and sometimes Aides; medicines such as anti-biotics and insulin given at irregular intervals and sometimes not at all...all these things and many more happen every day.

Sedative type medicines are given sometimes without a prescription by CNA's just so the patient will sleep and won't be a bother to anyone.

Diapers changed and patient not cleansed so that open sores develop and become "bedsores", sometimes as big as plates and so deep the bone is exposed. I have seen spines exposed, and hip bones open so that you could see the exposed bone move. And no pain killers ordered for these patients because the supervisor insists that "these people do not feel pain like other people."

I have seem them drugged to the point of death, and withdraw to the point of clenched teeth and inability to eat and it be called a virus. I have seen them sedated and it be called the flu.

I have seen diabetics go to the hospital so dehydrated, it would be better if they didn't recover and families hope they don't, because they know they will have to go through the "near-death" syndrome again and again, before they succumb.

When nursing home patients die, there is no autopsy performed to confirm cause of death. Murder by neglect is accomplished everyday in nursing homes. Murder by abuse is almost as common.

There comes a time when there simply is nothing else you can do for an elderly patient and time must take its course. But for the most part, this time is hastened by the neglect and abuse and these persons lives become long months of pain and hopelessness and helplessness. Alzheimers disease patients are particularly subject to these kinds of neglect and abuse because usually their bodies are in good shape, but it takes a long time to work the damage to the brain severely enough to die. They cannot complain (they lose their ability to understand words or speak in any way) and are completely at the mercy of those who care for them.

In the meantime, aides and nurses get impatient and careless; teeth rot and abcess, and go unnoticed because the patient does not know how to complain (if you know what to look for you can see the agony); impactions go uncharted; bladder infections go untreated with all the painful effects; bones deteriorate because of lack of calcium and food supplements; ear infections, colds, flu and pneumonia go untreated, usually the patient lives over them, but in a debilitated state, ready for the next infection. Other dread diseases take over and not diagnosed until treatment can only be "to keep them comfortable."

I am not talking about the "worst" nursing homes in the state, I am talking about some of the best. The worst, I'm sure, do the same kinds of things but to a greater degree. They perhaps are not as clean, not in a better location, not staffed by religious, etc., but the things I have outlined above happen in some of the best nursing homes, in good locations, staffed by religious, are kept cleaner than most and charge higher fees.

Please accept this, grammatical error and all, as I am writing off the top of my head from many years frustration and emotional scars. I have for the past 3-4 years kept daily documentation - though not as thoroughly as I should, on my mother and her incidents - but when I complained for other patients and their rights, I was told bluntly by the administrator and director of nursing that it was "none of my business." In previous years when I called the Area-wide Aging Agency and Omsbudsmen's program, they sent a lady out to look at my complaint of a senile patient having bruises on both hips and a broken pelvic bone and didn't even ask to look at the injuries. Instead they talked to a Sister in charge and took her word for it in spite of my allegations, and further did not even give me a report on the incident as required by law. I am happy to say that when I called for help on the last falling incident, when my mother's rib was broken and she was scratched and badly bruised, the incident was investigated directly by the DHS. Not only that, but the persons investigating looked at the person I had called about previously (as she was lying next door to my mother rotting of bed sores) and insisted on proper treatment and medicine for the lady. But this has only been within the past year.

This is not an uncommon type of incident.

I know this is long, but I hope you have read to the end. I am speaking for thousands of helpless people in nursing homes all over the United States. I read about similar incidents in the newspapers, and people think they are isolated incidents - indeed they are not. It's just that only a few make the headlines. The tragic counterpart to this story is that families do not oversee their family members in a nursing home. They trust the homes, and do not look into why Aunt Sally seems to be failing so quickly, or why Mother seems to have had a stroke (a standard excuse when a patient looks dreadful) or even sadder to say, and I would not have believed it a few years ago, children who literally take their parents to a nursing home and abandon them. They never oversee their care and in many, many instances are just glad to be free of the burden, and apparently do not care what happens as long as they do not have to take care of it. I'm sure this is one of the prime reasons abuse and neglect is so widespread and surely why it flourishes in our society. It is indeed an American shame!

Sixty minutes did a marvelous article on two ladies who were appalled at the conditions of a nursing home in their area, but before anyone could see the things they saw, the nursing home had had time to make the place look nicer, and therefore the abuse and neglect could be explained away as more acceptable.

Also, when most people go into a nursing home, they see the "respectable" locations. Few people go into the "heavy-care" wards of nursing homes where the above things take place regularly. And you could fill a book with the excuses offered----low pay, hard job, etc., but when you come right down to it, it is pure greed and lack of enforcement of laws already on the books.

I wish we could put every nursing home on notice that they will be inspected and fined for violations every month. I think hitting them in the pocket book might help decrease the tremendous profits they take from these old people, because giving them six weeks to clean up and paint up before inspection and then extending the time to comply indefinitely is simply not getting the job done.

There is so much more I would like for you to know, but if even this helps to substantiate what the people before you are telling you, I'm grateful for your time. Believe me, I know there are worse incidents that the light of day shall never see.

Sincerely,

Dana Boade

Oklahoma City, Oklahoma 73106

(405) 524-0834

cc: Vickie Miller, DHS

February 12, 1985
Elizabeth Plasick

Portage,
Michigan 49002

My involvement is the Governor's Mental Health Advisory representing consumers and relatives, Consumers and Providers United, board member of Citizens for Action in Mental Health in Lansing, Psychistric Alternative Alliance, formerly a board member of Kalamazoo County Community Mental Health board and committee member of the Program Planning and Evaluation, a member and board member of S.H.A.R.E. in Kalamazoo, Citizen's Advisory Council of Pheasant Ridge (a children's psychiatric hospital for the state of Michigan) in Kalamazoo.

Five years ago, the former Director of the Michigan Department of Mental Health initiated consumerism in mental health. Dr. Frank Ochberg appointed a consumer to the Governor's Mental Health Advisory. Michigan Department of Mental Health funds Citizens for Action in Mental Health. This organization is unique for its representation of consumers and their relatives. Self-help, support groups are croping up all over the state of Michigan.

In Kalamazoo, Michigan, a branch of C.A.M.H. exists at Edison Neighborhood Center. Our project was to stop abuse in the children's unit of Kalamazoo Regional Psychiatric Hospital. Staff complained to Recepient Rights at the hospital. Their concerns were not acknowledged. Issues were drugging a young man for the purpose of cutting his hair. Coed activities were stopped and staff were concerned that this was not normal. Children smashed windows because they were angry with their treatment. They were detained to the facility, outside activity was cut off. We were concerned about these children and contacted the Children's Defense Fund in Washington, D.C.

The Michigan Director of D.M.H., Dr. Frank Ochberg was asked to meet with C.A.M.H. in Kalamazoo. We threated a class action suit if something was not done. In fact, we had a lawyer present. He repesented two young adults who were in the children's unit. These youngsters spoke out about the treatment to the director. The staff were present to voice their concerns. The director of D.M.H. was convinced and ordered the Children's unit of K.R.P.H. to be sepertated and a new director hired. Pheasant Ridge now has a Citizen's Advisory Council of which I am a member. Members have access to the facility.

S.H.A.R.E. , a parent, relatives and friends self-help, support group was started in Kalamazoo with support from the Kalamazoo County Community Mental Health Board.

One of our members was having problems with her son's treatment at the state facility, K.R.P.H in Kalamazoo. Her son was not getting proper treatment. He was overdrugged, unkept, his belongings were stolen, sexually abused by another patient. She asked her physician to check her son's vital signs. He went with her to visit him while in the hospital. He observed that the whites of his eyes were yellow. He immediately advised her to transfer him to another hospital. After his visit, she requested to see his psychiatrist. She was upset with his lack of concern and his response. He asked her, "What is your problem?", referring to her past experience as a patient of the same facility. She was under stress as an elder and her son was being mistreated and no one was doing a thing about her concerns for her son. She informed her lawyer of the status of her som. I suggested getting in touch with her congressman, Howard Wolpe. She did that and requested his help to get her son transferred to Fort Custer in Battle Creek, Michigan. She was successful in getting him out of the state facility. He is now doing much better.

His physical condition has improved so has his care. There is also contact with the elder.

Another mam who was a patient at Kalamazoo Regional Psychiatric Hospital fought being given drugs, was thrown in seclusion, given the drugs against his will, was found dead later. His friend was despondent and committed suicide in the same facility. The family of the man who died in seclusion was angry with the treatment. The case was followed by the Kalamazoo Gazette. The family asked the Kalamazoo County Prosecutor's office to investigate. Nothing much was accomplished by this office. Consumers did appeal to the D.M.H. and the Mental Health Advisory to the Governor. A Death Study was done. The results of the autopsy was not publicized.

A newly hired attendant at K.R.P.H. was assaulted by another patient. The other attendants did not care about this young person's concern for the patients because it interfered with their card games or reading the paper. They set her up by telling a patient a fabricated story and when the young attendant was alone on the ward she was beaten by the patient. She quit working at the facility but has seen a lawyer for possible legal action against the attendant or hospital.

At a Mental Health Advisory, an elderly couple told of their plight of their son who now is in the state prison at Jackson, Michigan. He and the family begged for help from Kent County Community Mental Health in Grand Rapids. The reason why he is in prison is that he was accussed of robbing a convenience store. His only weapon was a rolled up pair of underwear that he had in his pocket. He had been living in the streets, sleeping on park benches. They claimed that he did not receive adequate mental health care in prison.

While in prison, he fed the pidgeons with bread that he had saved from his meal. He was ordered to isolation. The parents expressed their concern that he did not belong in prison and lack of care for mental illness.

In 1984, the Kalamazoo County Mental Health Board's program of Community Placement had many case managers leave for other employment. The problem was of concern to the Recepient Rights Advisory to the mental health board. There was no solution to the problem and it was referred to the state Recepient Rights Advisory. Members had requested to see the exit interviews to find out what the problem was. Not enough time is spent with clients. The paper work is a burden and sometimes overwhelming. People get burned out. The director of the mental health board denied the exit interviews. That prevented the recepient rights advisory from finding out the reasons for people leaving the mental health system. When a client has a new case manager, that might be upsetting to the person and they sometimes go into crisis and return to the hospital. This can be expensive. The client needs stability, not shoved around from program to program.

The future for mental health services in unclear with the looming federal budget cuts, deficit spending. Budget cuts seem eminent. The counties have already cut to the bone their budgets. Will the mental health system suffer and the system return to earlier times of snake pits? When our President was Governor of California, the mental hospitals were in deplorable condition.The statement was made by a Scandinavian when he visited the state facilities in California, that animals live better and are treated better than people who were in the hospitals. Our president blamed the unions for stirring up

(5)

trouble for the publicity and they were not concerned for patients. Does J.A.C.H. reveal treatment issues? An audit is advised. It gives a clearer picture. J.A.C.H. is concerned with bricks and morter. They do not receive a clear picture of treatment issues. More needs to be done. In Michigan, consumers fought at the state level for external legal advocacy and now this year this will be funded by the state legislature.

The Association of Retarded Citizens have been instrumental for those of us in the mental health system. Mental Health has the tendancy to isolate us because people are hesistant to speak out because of the stigma.

CONSUMERS OF THE MENTAL HEALTH SERVICES NEED TO BE HEARD AND TAKEN SERIOUSLY FOR IMPROVEMENT OF SERVICES.

MORE RESEARCH IS NEEDED, ESPECIALLY ON GENETICS, DRUG-FREE TREATMENT, CONSUMERS AND PROVIDERS SPEAKING TO ONE ANOTHER TO IMPROVE SERVICES, PROFESSIONALS HELD ACCOUNTABLE, STRICTER ETHICS, LAW ENFORCEMENT FOR MAL-TREATMENT.

AN ONGOING DIALOGUE OF CONSUMERS AND PROVIDERS IS NECESSARY FOR CHANGES TO BE MADE TO IMPROVE SERVICES.

Elizabeth Plasreck

APR 0 3 1985

Lowell P. Weicker, Jr.
U.S. Senate
Washington, D.C.

Dear Senator Weicker,

I read with gratitude this morning news reports of your efforts to help mentally ill persons confined to state institutions.

As you begin your investigations, I would like to bring several associated issues to your attention.

The tragic reality is that much of the mental and emotional illness that results in hospitalizations is amenable to intensive therapy but several structural situations make it nearly impossible for anyone but the wealthy to afford proper treatment.

Specifically, private medical insurance discriminates against psychiatric fees compared with fees for routine medical care. Intensive therapy is expensive and far beyond the financial reach of most American families. To make matters worse, in the last several years medical expenses have been deductible for federal income tax purposes only to the extent that they are more than 5 percent of adjusted gross income.

While the plight of persons confined to state institutions is clear, what most do not realize is the incredible situation faced by countless persons, such as sexually abused children who are increasingly the stuff of newspaper headlines, as they try to live with the effects of their experiences and cannot afford the therapy that would heal them. The innocent victims of these crimes face tens of thousands of dollars of psychiatric care, if they are so lucky as to be able to afford it.

Ironically, studies prove quite clearly that persons who do not get proper psychiatric care are overusers of medical personnel and facilities, thus driving up the costs of services that cannot cure. The effect of emotional problems as witnessed through diseases such as stroke, heart disease, cancer and diabetes are also well documented.

God bless you for whatever you can do to rectify this horrible situation. It is the mark of the statesman as opposed to the base politician to help those who cannot repay in the form of votes or power.

Sincerely,

Pamela J. Meyer

Pamela J. Meyer

Kirkwood, Mo. 63122

Jeanne Bell
Cedar Rapids, Iowa
52404

March 6, 1985

At this time I do not have the exact date of my admission at St. Luke's Psychiatric Unit. It was in 1983, early spring, about February. I had a depressive disorder due to situational and somewhat seasonal. My chemical balance was "borderline", so I was told. I had received 12 ECT's along with meds. In early April I was told I would soon be released. My admission was voluntary and I have never been committed. I was permitted open passes & was on an open ward.

Because of previous experiences at this hospital, I was cautious of the staff & kept much to myself. I had seen too many unreasonable situations. – In the evening of April 7 1983, I had come back from a pass, with my husband, from visiting my ill father in another hospital, out of town. He had been put on life support & I became upset of the incident. Due to this, I had a disagreement with my spouse. – I arrived at 2245 & from showing

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stress, was told to go to my room + did so. I was given Valium 10mg. intramuscular at 2300. I conversed somewhat with a staff member. At 2310, I was given trilafon 4mg. by mouth. At 0010, trilafon 6mg. & cogentin, 2mg was given by mouth. 0100 trilafon 6mg. was given. What was strange, is on my charts I *am* not to be given "anti-psychotics" due to drug reaction. - I had been in my night wear + in bed. At 0105 a nurse came in + told me to get up, that I *had* *to* go to 2-East, which is a locked unit. My response was "No, I do not want to go there!!" She said again that I *had to* go. I asked her why?, I had done nothing wrong, but received no explanation (2 East is well known for a "punish-ment" area if too much emotion is shown + patients feared it!) I felt frightened + crawled out of bed + walked out of my room with a nurse. As I walked out into the hallway, *I was* face to *face* with 2 Cedar Rapids city police officers + 2 St Lukes security guards. Fear + bewilderment was my immediate feeling, so I turned to run back into my room. As soon as my back was turned, I was tackled from behind by all four men and thrown face down on the floor. One guard sat on my back, and hand cuffed my hands behind my back. He then twisted them + clamped them so tight that it was cutting into my wrist. So I cried out for help He grabbed the back of my hair on my head and started slamming my face into the floor. At the same time he would push my cuffed hands up towards my shoulders causing tremendous pain. The other guard started kicking me in my right side as the 2 nurses, 2 police officers, + patients watched. I then was dragged, face down, by the cuffs, down the hall to the elevator. I was very weak + in much pain, but tried to stand up at the elevator. I was pushed around + laughed at. When I arrive to the locked floor, I was stripped of my pajamas infront of all involve, placed in full leather restrains + left in a locked room. I was let out of restraints on the morning of April 8, 1983. I was in much pain + my head was throbbing. I was assigned to another room on the locked ward + given a darvocet for pain. I looked in a metal mirror + my right side of my face, eye, + head was swollen + bruised. I had bruises all over my body + my wrist had abrasions from the tight cuffs. I was frighten + requested to leave. I was told I was on two-24 hour holds, but never a magistrate nor anyone else ever came. I kept asking what I had done so wrong to deserve what happend. No answers. I did not have any privledges, but finally was able to use a phone monitoring my conversation. I immediately called an attorney + he told me the hospital was completely in the wrong. But nothing was ever done. - April 9, '83 I went back to an open ward & there is where I found out from fellow patients who had done what to me since I was on my face & couldn't see. At that time, no one seemed to understand why every thing happened as it did or for what reasons. - On the evening of April 11, 1983, I was found slumped over in my bed. I was told later I was pale & incoherent. I awakened in E.R. on a heart monitor & then placed in I.C.U. Apparently my heart was going into an arrest. I was accused over & over of taking an overdose but nothing was found in my urine, blood, or smears. I was again locked up on the closed floor. The things I saw happening there were overwhelming & almost unbelievable. - In the latter part of 1983 I filed suit against St. Lukes & it still is in litigation. I can not believe the lies & harassment, but I will not give up.

Lorine Bell

Dear Joyce,

If there is anyway possible for some assistance, feedback, or anything, it sure would help. I have several witnesses but they have become passive + frightened and I am trying not to really involve them. The "main 'record' witness, who from the very beginning claimed to have witness everything + has been standing beside me," has given me a great fall! I have just found out she had not been there at the time I saw it. It makes a statement a conspiracy between the two of us against [illegible]. It hurts. I trusted her honestly without checking things out, which is difficult since files are suppose to be confidential. Also my nurse notes it states that I appeared to try to strike out at a nurse, as I turned + was thrown to the floor. At depositions, many completely different stories have been told by staff. I feel very much alone, but still have two fine attorneys. But I fear they may give up.

Joyce, I would appreciate any help. I have dropped all of my physical activities since this incidence + have semi-secluded myself. - This is not me! I even gave my two horses away, which at one time, was great therapy. I [illegible] to have + relatives shun me + it hurts deeply. Just recently I began a class in EMT-A, hoping by getting out

over

again & trying once again to expand my mind and try to get back some self esteem - I need it! I was also informed that I would have to be re-program back into society. nothing has ever come of that either.

If you need more information, contact me & I will try to do my best to help you to get some change to occur in this area of problem.

Best Wishes for All of
you in Washington. D.C.
I know now someone
does care & is trying.

Jeanie

Alan Clinton-Cirocco
1243 Heritage Drive
Troy, Ohio 45373

MAY 2[illegible] 1985

May 23, 1985

~~Senator Lowell P. Weicker, Jr.~~
Subcommittee on the Handicapped
303 Hart Senate ~~Office Building~~
Wahington, D.C. 20515

Dear Senator Weicker,

I was employed at Oakwood Forensic Center (formerly Lima State Hospital) in Lima, Ohio from January 3, 1983 until July 13, 1984. My position was that of Social Worker IV. My responsibilities inclued individual and group therapy, in the preparation of the patients to return to the referring correctional institution. All of these patients were probated as Mentally ill and dangerous to themselves or others.

I send you this information so that it can be included in the hearing's final congressional record. I will list for you the incidents of verbal, and physical abuse that I have seen or that I can verify.

1. Patients were verbally abused daily by the psychiatric attendants.

2. Psychiatric attendants physically abused patients by either beating them, locking them in their cells or strapping their four extremities to the bed posts. One technique that was used regularly was beating the patient into submission after he was four wayed to the bed.

3. Psychiatric attendants would warn socialworkers or other staff not to say anything because they would suffer the consequences if they reported it.

4. Two of the attendants who severely beat patients were promoted up and out of patient contact.

5. Psychiatric attendants would supply drugs and alcoholic beverages to patients.

6. Psychiatric attendants would tell physicians the amount of psychotropic medication to prescribe to patients.

7. Psychiatric attendants would verbally and physically stimulate patients into a "frenzied" state while in seclusion, just before a qualified mental health professional would assess the patient. Therefore, the patient would remain in seclusion.

8. Patients were stripped of their dignity on the "closed wards". They were made to submit or be beaten.

9. Psychiatric attendants resisted all attempts made by the

professional staff to initiate therapeutic change in the patients.

These are just a few of the abuses that still occur at that facility. Please feel free to contact me if you have any questions. I would like to see the bill, S 974, put a stop to these injustices.

Sincerely,

Alan Clinton-Cirocco

Alan Clinton-Cirocco, MSW
1243 Heritage Drive
Troy, Ohio 45373

TESTIMONY ON PSYCHIATRIC ABUSE

by Irene Koch

submitted to the U.S. Senate subcommittee on the handicapped

My first hospitalization was in 1975, and all subsequent stays have been in the same hospital. Testimony on what led to this is available on request. I have never taken any hallucinogenic drugs. In 1976, an occasional condition developed, which I call a "separation" and which my doctor calls a "depersonalization". In the hospital, on January 13, 1982, I discovered some change missing from my purse, and I yelled down the hall, "I hope that whoever took the money out of my change purse will return it, and not use it against me!" This was considered sufficient reason to give me an injection of Haloperidol, despite my explanation that if I yelled the message loud enough just once, it would get to the source of the problem. Soon afterwards, I was doing dance and exercise in the wide hallway. I was approached by a nurse, who said, "You are agitated. We are going to have to give you an injection." It was given to me against my will both times with about four staff members ganging up on me, when all I did was refuse to take the medication. What followed was an 8 to 12 hour "separation", one of the worst I ever had. On Jan. 14,1982 I managed to write a description of it,my second written description of this terrible physical and experiental condition. Here is an incorporation of it into this testimony.

I had not experienced it for several years. I took a shower, felt relaxed, came back to my room and then it started. A separation: that hideous out-of-body experience. It is stronger that what self control can manage.

At first, there was trembling in my feet and hands. This was followed by a feeling that my face was looking at me from a short distance away,including my back and the back of my neck. Mirrors seemed to intensify the discomfort. I got a phone call from a friend which I could not continue. I had to hang up abruptly. During this phone call, I recognized the usual time lapse that I experience during a separation. Not only was there so much time between my spoken words; my words were caught in a psychic hollow and I felt that I needed a lot of power to force them out. I could still speak, but I felt this speaking would stir up my psychic interior, the sound, word by word, sending waves within me and outside of me and plummet me further into the separation. Hospital staff entered the room as I was lying on the floor, trying to hyperventilate in order to pass out. There were dual time frames; I perceived the staff speaking to me, in a form quick and clear; while when I spoke, there was the usual desiring to describe in detail about what is happening to me with the obstacle of a sluggish time fabric. Meanwhile, between my words was my head filling with instigated mechanisms from past separations, such as voices, extremely strong suggestions, and visual reflections. The strongest was the dilemma/decision to kill myself in order to get relief. "Okay, I give in to death/"No, I want to live. I cannot give it up." I then tried to stab myself in the chest with a can opener I got from my purse. The staff came in and took me to 1H, put me in seclusion and strapped to the bed. Again the dilemma/decision to die or live continued on as the whole separation persisted. Interior visual images exacerbated the separation. Suggestions from past occurrences combined with the new style continued to make it worse. My body got tense all over, I was trembling and my feet were sweating. The worst was the way the predictive mechanism coupled with scenarios, not necessarily willful because of their compulsive nature, would affect both my direct environment, such as my body, and what I fear: deaths of people close to me being caused, catastrophes, holocausts, destruction of whole universes-so real, so unrational,so physically felt. There was a duality of communication; voices condemning me for being destructive and usurping all the resources (ie. "There's only three universes left", said a voice several times) and another was a suggestion (almost voice level) threatening to shove horrid patterns into me to the point of no return. Off and on, I felt like such a menace that I should die to stop the destruction as well as to get relief. Yet I also began to fear all life gone from around me and I would be alone strapped to my bed. Off and on, I said that I must succomb to a heart attack. Off and on, I said let the suggested scenarios of assassination plots against me take place.

Throughout the separation, even at first, I have the indecision as to whether I should try to close my eyes and try to relax or to concentrate on the immediate environment which I see in attempting to relax. The worst sensation in this context is feeling myself look at the back of my head and neck. The predictive mechanism starts quite early. As the separation escalates, the tension in my body increases.One way the predictive mechanism operates with my body in this particular instance is that I told myself that I needed to urinate, and then predicted that by the time I got the pan that I really could not. Beneath the surface, I actually did need to urinate. This self suggestion came out of the compulsive predictive structure of suggestions coming into my head. Later on, suggestions said I would get relief from the whole separation if I urinated in my bed without the bed pan. Then I began banging my head on the rails on the sides of the bed. The hospital staff rushed in and tightened the restraints, particularly those across my chest. I had bruises and a sore spot on my head and chest to remember this by, among other things. Requests made earlier to be allowed to go to a regular bathroom were denied after being put into restraints. As the separation wound down, I felt freer to try yelling it off out loud,several repetions of "Never again! End the torture!" which referred to the whole separation and how people were dealing with it. My hips had muscular soreness from all the injections I got throughout the night. My neck felt strained and sore from me trying to choke it. It finally began to let up. The residue left was muscular tension: I needed the small of my back, the back of my neck, and my right arm massaged, as well as other parts of my body. Most of all, I needed release from my restraints, so that I finally could get some sleep. Finally, I got released from my restraints-without a massage; nonetheless, I did get to sleep. It is ironic that throughout the night,I saw staff peer in the window and would try to unlock the door and would go away except for what I mentioned above. I wish I could have claimed my will and successfully sent suggestions to end the separation itself, but my body and brain felt an incredible invasion of privacy with a hospital staff that did not believe in communication and compassion to deal with the problem.

Prior to my next admission to the hospital next year(1983),I had been gradually stopping lithium over a period of several months, because I was having kidney dysfunction from it. The physical abberations involving mood displacement and tone in my stomach got more frequent and disturbed me in trying to fall asleep at night which led to another hospitalization, after medication adjustments were not successful, producing two separations in midday, despite primadone successfully stopping separations for quite a few months(an anticonvulsant, epilepsy not indicated).I was ambivalent about going to the hospital again, not trusting any hospital, not knowing who to turn to,with no approriate resources provided to me. I have incorporated another statement of my being abused in the hospital.

On April 29,1983, at about 4:00PM, I entered Washington Hospital Center, unit 3M.Prior to that, my parents and I had spent an hour in Dr. Lofft's office, while he prepared treatment orders which we thought would prevent my having a separation. I had contention with the behavior modification clause in the treatment plan we were all working on. That is why I did not sign the hospital consent form, with its short, open ended statement, because I remembered the bad set of experiences I had during my previous hospitalization.

When someone came to take my blood, I refused, because the nurse said I had to put on the patient wristband in order to have the blood test. I told her,"I refuse the patient wristband, because I have not signed in yet. No blood test was taken.

No medications were brought at dinner, which is when I usually have my vitamins and supplements and primadone. After dinner, they brought some pills, including two red pills (Serentil),and I panicked, forgetting to ask for primadone. This panic was based on two separations, two days in a row, apparently as a result of taking Serentil in excess of 100 mg. in 24 hours, and too early in the day. A couple of times I had taken the drug at dinner instead of at night, and gotten those bad stomach moods. I had noted that the time factor of how fast it works did not correspond to what was said in the medical books.Taking the Serentil with tryptophane had not helped either. I still had to take Clonopin to stop the separations.

In Dr.Lofft's office, I had asked,"Why does the drug which precipitates the bad syndrome in my body act so fast, and the drugs that are supposed to help take so long?"So when the staff told me to take the Serentil,I debated them to keep from taking it too early,in order to keep my composure. One person told me that there might be fewer milligrams in each tablet,but it was still too early in the evening, and I was still scared. A nurse said it was either the pills or a shot of Serentil.I continued to debate to hold off either one.

Then the nurse returned with the shot, and I pleading,"I'll take the pills!" The response was,"You had your choice earlier." I was surrounded by staff, taken to my room, and given the shot.

They would not allow me to talk to Dr.Lofft between the time I was first offered the pills and got the shot,despite the report to me that they were talking to him about the situation. Another patient was protesting their treatment of me,"Let her talk to her doctor!" Later, she was put in the seclusion room,which may have been connected to her protest.

Soon after the shot, I felt a mild delirium in my head and a dizziness. The backbone effect started to surface,but remained a while in a contained state. I wandered about the unit and knelt by the fan; there was something wrong with air-conditioning. I felt my equilibrium begin to shift(psychic yet within my body) to a loss of equilibrium.Earlier, in the admidst of the debate and the articulate expressing of my fears, reciting past history of what the drug does to me,someone mentioned the phrase"self-fulfilling prophecy", which I had rebutted by saying that I do not ever wish to have harm on or in my body again; I do not wish this psychic aberration at all ever agin.

Earlier the staff had received a copy of the treatment plan worked up in Dr.Lofft's office and "Notes on a Separation" from the Jan.,1982 hospitalization. When I felt the loss of equilibrium, I was pitched into a separation,and heard an aide I remembered from my previous time in the hospital say,"I wish I could fall like that." when I fell on the floor during my first bout of dizziness. I again began hearing the voices so closely connected to what my body was going through, physical indictments landing on my body and pushing from within. During the day, I had been reading a letter from a friend(It came just in time!) During the separation,the diatribe of the voices incorporated a book,"A Woman on the Edge of Time",which I had brought to the hospital, into my feelings. They said that I was sacrificing my friend who had written the letter,or that she was suffering unduly at the same time.I could not even read the letter at this time for fear that this would happen or that I would suffer more. I told the staff I was in a separation, but they did not believe me at first.

I could not ask for massaging of tension out of my body,mostly my back, because I did not trust the staff. I was astounded that Dr.Lofft had ordered this drug for me at this time,after all that I had told him. I questioned the interpretations of orders by the hospital staff and after the plan and "Notes--" they had been given to read, and the discussion I had offered. The separation this time was at least shorter in duration. Time is distorted during a separation,but it seemed to take awhile,until I was given a Clonipin and two green pills,which I later learned were Chloral Hydrate. For that day,I never got

3 of my 5 Primadone, Tryptophane, or my dinner supplements,all of which might have eased my suffering. But I did finally get to sleep finally.

The next day, I reported the separation to my therapist(Dr.B.R.),my parents, and B.C.,advocate from Montgomery House. After intervention, the staff agreed to only 100mg. of Serentil at 10 or 11PM, with Tryptophane two hours earlier.

Session with Dr. DeMars 11:10 AM April 30: The staff told Dr. DeMars that I refused the Primadone. See report; I refused the Serentil at the hour it was offered; I never refused the Primadone.I was too upset to ask for it.

Session with Dr. DeMars May 2:He does not acknowlege conspiracies in connection with my case as well as Dr.Lofft. This time he said,"You know you have paranoid delusions" After some conversation,he briefly admitted,"We know there are conspiracies in this world." I said in reaction, "but they are connected to us; we exist in this world."Then he said,"I want to increase your Serentil if you don't improve." I felt threatened, based on past experience.I got upset,especially when I reacted to his diagnosis of me as a psychotic and responded:" Do you know what these terms represent? I am a person. I can't take any more Serentil, for God's sake(etc.)!" He stormed out of the room.

May 4: No fruit juice all morning,no offer of cranberry juice. Mid-afternoon a Recreational Therapist came in with a Tab;I asked for some. Staff said I couldn't have any. I slammed a cup of ice on the floor and said,"I think it is cruel of you to drink this in front of me." She apologized;rest of staff did not. I started throwing a fit about feeling deprived. Finally had a small cup of orange juice at 3:45PM and refused the Serentil offered to me because I was"agitated". A little later I called my mother,because I was afraid they would force Serentil on me again. My mother came over at 6:45PM to see me. Since Dr.DeMars would not promise that Serentil would not be forced on me again, I signed out of the hospital,"Against Medical Advice". (This took two hours)

To this day I have not been in the hospital since. I would not know where to go. My true problems are not taken seriously. Assumptions:layman or professional,biochemical or otherwise, are taken seriously. Irene Koch 4/8/85

Address: 507-D#6 S. Frederick Ave. Gaithersburg, Md.20877 U.S.A.
Telephone: 948-7605

FAMILIES UNITE FOR MENTAL HEALTH INC

P.O. Box 126, Oreland, PA 19075 • Phone (215) 572-1394

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March 22, 1985

Senator Weicker, Chairman
U. S. Subcommittee of the Handicapped
113 Hart Senate Office Building
Washington, D. C. 20510

Dear Senator Weicker:

I am aware that you will be holding hearings to consider conditions in institutions for the mentally ill. I am writing to you in behalf of my son, who is hospitilized in Haverford State Hospital in Pennsylvania.

My son is 22 years old and has been ill for 5 years. Our experience in the mental health field includes three private hospitals, schooling while ill, and two state hospitals; Haverford and Norristown, all in the State of Pennsylvania.

While my testimony is not one of blatent brutality, it is never the less one of subtle neglect. I will try to convey to you the sorrow and frustration of a mother trying to do battle with a mental health system the neglects and worsens the condition of her son.

My son has remained on an intake ward whose very nature is chaotic and turbulent. The intake ward is not only used for the evaluation of acute incoming patients but unfortunately is also the long term ward for poor functioning patients. It has been documented that my son must have a stable, strictly regimented environment if he is to maintain and improve his level of function. Yet, he is a captive of the very environment that worsens his condition, resulting in his having been placed in restraints for a 6-month period. He became hunched and developed body sores caused by the leather straps rubbing his skin.

After 6 months, he was transferred to Norristown State Hospital where the restraints were immediately removed and his mental condition improved, as he was placed in a small (14 bed) ward with a well trained staff. Why did he have to spend 6 months with his arms tied to his side before being sent to an appropriate unit that was able to maximise his improvement? Worse yet, why, as soon as he was stabilized, was he returned to Haverford to have his condition deteriorate? Appropriate wards must be the rule in order to maximise the patients stability.

For 4 years I tried to obtain dental care for my son, in both private and state hospitals. Dental care for the resistive is neglected. Six months of persistent prodding of the staff dentist at Norristown didn't assure my son decent care. One call to a private dentist and in 45 minutes he had arranged everything. The result of the State's neglect; 3 non-restorable molars that were extracted and 12 cavities filled.

My son is on Tegratol, a potentially lethal medication that can cause animia and must be monitiored frequently by blood level testing. Several days ago, I asked the unit nurse to check his chart for this testing. No reports were listed and she could find no orders written. Monitoring of these extremely potent drugs must be enforced.

Every other week I take seven changes of clothing to my son because they manage to "disappear". How would you like to visit your child in December and find him sitting in a buttonless coat because there were no shirts on the unit. A staff member sitting with him was unaware he had no shirt on and that his pants were not zippered. Private business investigates and controls misplaced property but state hospitals do not. For the involentarialy committed patient, the hospital should be acting in a fudiciary manner to protect the patient's clothing and should do their utmost to prevent the loss of any clothing.

There are specific means of measuring a patients functioning level. The functioning level can change from day to day and may require adjustments of medication. Trained, experienced psychiatric nurses are needed to accurately translate observations of patient behavior into measuring criterion. I doubt the quality of this reporting when only one nurse oversees thirty patients.

As I have already stated, the large wards are turbulent and chaotic where just visiting for a short time leaves the visitor exhausted. Yet, due to staffing shortages many of the staff are working double shifts. No wonder staff often fails to succeed in modifying patients behavior. There are many fine, concerned individuals working at all levels, but the poor working conditions of overcrowding and understaffing restrict their benificial activities.

I hope that I have conveyed the dispair I continue to feel in seeing my child, who at 17 had a bright, fulfilling life ahead, become as a result of a brain disease, a shell of his former self, **neglected and worsened** by the very system that has been provided to help.

Sincerely,

Mary Ellen Rehrman

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Developments in Patients' Bills of Rights
Since the Mental Health Systems Act

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in press

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Developments in Patients' Bill of Rights
Since the Mental Health Systems Act

I. Background.

The Mental Health Systems Act of 1980 [MHSA][1] was a comprehensive Federal statute on the provision of mental health services, intended as a legislative realization of the 1978 Report of The President's Commission on Mental Health.[2] The Commission and the MHSA were important initatives of President Carter; however,the MHSA did not survive the Carter administration. Most of the statute was repealed, soon after President Reagan took office, by provisions of the Omnibus Budget Reconciliation Act.[3] One MHSA section that escaped repeal was Sec. 501, the Patients' Bill of Rights.

The MHSA Bill of Rights may have survived because it was considered relatively harmless. As that section had been originally reported out of Senate committee, it had provided for enforcement of the rights of consumers of mental health services through individual cause of action and through cut-off of funds but, as amended on the Senate floor and finally adopted, all the enforcement provisions were deleted. (The terms "clients" and "consumers of mental health services" are used by some instead of the traditional term "patients".)

The Senate debate on Sec. 501 indicated that Congress assumed that existing state laws on patient rights were generally already sufficient.[4] The provisions of the MHSA Bill of Rights as enacted were therefore not made mandatory, and merely recommended that the states "review and revise, if necessary" their state mental health laws in light of the MHSA rights. In a previous study,[5] however, we found great disparity between the level of rights protection granted in most state statutes at that time, and the rights Congress recommended. The Congressional assumption as to the then current level of state statutory protection of patient's rights was in error. Substantial amendment of state laws would therefore have been needed to meet the standard declared by the MHSA. (Judicial decisions and administrative regulations in a number of states had recognized additional rights not surveyed in our previous study.)

Five years have now passed since the MHSA was enacted. The current study tests whether the Congressional recommendation to "review and revise" state rights statutes has been carried out. Caselaw and administrative regulations remain outside the scope of the study.

II. Method

We attempted to determine whether any legislature conducted a full-scale "review and revis[ion]" of its mental health rights laws since 1980, anywhere in the 50 states and D.C. We examined the statutes to determine if any jurisdiction had adopted additional rights, or amended existing ones, for consumers of mental health services. We also sent several waves of questionnaires to the commissioner of each state department of mental health [DMH] and the president of each state Mental Health Association [MHA]. We asked these informants whether and how their state laws had been revised, as a check on our independant research. We also asked them whether, if there had been revisions, the content of the MHSA recommendations, or the fact of Congress' request, had played a part in the changes of their state's law. In addition, we invited their comments on Congress' choice to pass in the form of law a recommendation to the states.

The return rate on our questionnaires was satisfactory: 48 out of 51 jurisdictions (94%) on the DMH survey and 22 out of 51 (44%) on the MHA survey. At least one or the other responded in 50 out of 51 of the jurisdictions (98%) including all of the states where our research showed that amendments had been adopted.

The MHSA Bill of Rights specifies its provisions in 25 subsections. State statute changes since 1980 correspond to 17 of them, which are summarized in Table 1.

[TABLE I goes about here]

TABLE I

MHSA Rights Affected by State Laws Since 1980

MHSA §501	Summary
(1)(A)	The right to appropriate treatment and related services in a setting which is most supportive and at least restrictive of a person's liberty.
(1)(B)	The right to an individualized, written treatment or service plan.
(1)(C)	The right, consistent with one's capabilities, to participate in and receive a reasonable explanation of the care and treatment process.
(1)(D)	The right not to receive treatment without informed, voluntary, written consent, except in a documented emergency or as permitted under applicable law for someone who has been civilly committed.
(1)(E)	The right not to participate in experimentation in the absence of informed, voluntary, written consent.
(1)(F)	The right to be free from restraint or seclusion except in an emergency situation pursuant to a contemporaneous written order by a responsible mental health professional.
(1)(G)	The right to a humane treatment environment that affords reasonable protection from harm and appropriate privacy.
(1)(H)	The right to confidentiality of personal records.
(1)(I)	The right to have access to personal mental health records and have a lawyer or legal representative have reasonable access to records if the patient provides written authorization.
(1)(J)	The right to private conservations, reasonable access to telephones and mail, and to visitation during regular visiting hours.

TABLE I, Continued

(1)(K)	The right to timely and meaninguful information about one's rights at the time of and after admission.
(1)(L)	The right to assert grievances with regard to the infringement of rights and to have a fair, timely and impartial grievance procedure provided.
(1)(M)	The right of access to, including private communications with, any available rights protection service or qualified advocate.
(1)(N)	The right to exercise other rights without reprisal, including denial of appropriate treatment.
(1)(O)	The right to referral as appropriate to other providers of mental health services upon discharge.
(2)(B)	The right to confidentiality of and access to records continues following one's discharge.
(3)(C)	The patient has a right that his attorney or legal representative have reasonable access to the patient/client, the facility at which the patient resides and, with written authorization, the patient's medical and service records.

III. Findings

A. National trend.

Our study revealed no widespread state movement toward reviewing and revising state statutes so as to adopt the consumers' rights recommended by the MHSA. Thirteen states have amended their patients' rights statutes since 1980; 38 (including D.C.) have not. The most changes were made by Mississippi (ten changes), Maryland (nine), Hawaii (eight) and Kentucky (eight). The other nine states made five or fewer changes. Of all the thirteen states that have amended their state code since 1980, only Hawaii statutes now provide consumers virtually all the rights recommended in the MHSA.

Nationally, there were amendments to state law involving 17 MHSA rights. The provisions most changed (five states each) involved the rights to a treatment plan, consumer participation in planning, consumer access to records, and after-care referral. Other common changes (four states each) changed provisions relating to the right to treatment in a least restrictive setting; treatment planning participation; freedom from restraint or seclusion; confidentiality of records; the right to private conversations, telephone, mail and visitors; being informed of other rights; and access to an advocate.

Of the 59 individual changes made, 34 constituted adoption of a right recommended in the MHSA by a state which had not previously granted it in any form. Nineteen changes were partial adoptions by states of MHSA rights previously not granted. Six changes were expansions by states of rights, where state law already had partially satisfied the MHSA definition of a right.

Table II sets out the extent to which the 13 states taking action since 1980 have amended their codes as to each of the 17 MHSA provisions. Table III is a compilation of statutory citations of these changes, so that readers of this article in any state will be able to confirm the text of the law and check for subsequent amendments or judicial interpretations. The text in section III.C, below, sets out a state-by-state summary of the changes.

B. Impact of the MHSA

Table IV sets forth responses to our questionnaire showing informants' perception of the effect of the MHSA on their state law revisions. The MHSA apparently had little influence in bringing about state revision of consumers' rights statutes. Of the 13 states making changes, officials in only one state (Hawaii) indicated substantial MHSA influence, those in five others indicated it had significant or some influence, and those in seven states indicated that the MHSA had no material effect. Of the 37 states that did not pertinently amend their codes since passage of the MHSA (not set out in a table), in 34 states the MHSA apparently had no influence. Ohio and Pennsylvania officials reported that their legislatures reviewed their state statutes in light of the MHSA, but did not revise them, as their consumers' rights laws were deemed sufficient. (Informants in one state gave no reply).

Developments in case law appear to have influenced state review and revisions of consumers' rights statutes at least as much as the MHSA. Officials in Alabama, Louisiana, Massachusetts and Utah indicated that court decisions, and not the MHSA, were a factor in securing consumers' rights. One informant, in Texas, reported that both caselaw and the MHSA influenced the legislature to amend its state's statutes.

Hawaiian officials were strongly influenced by the MHSA. The Hawaii Mental Health Association stated that the legislature's "total revision of our weak statutory Bill of Rights [was] based entirely on the federal Mental Health Systems Act Bill of Rights," and that the MHSA "served as a catalyst to initiate our review of the state statutes." It also reported that "[w]e use (and continue to use) the President's Commission report language in testimony, for background and for specific recommendations in patients' rights and on many other issues." The Hawaii Department of Health corroborated that assessment of MHSA influence on Hawaii law.

Our questionnaire also solicited comments on Congress' choice to pass a purely advisory act. The Minnesota Department of Mental Health and Mental Hygiene reflected the sentiment of several state officials who responded to this question:

> "In my judgment, such recommendations will not have very much significance in very many states and this compromise, I think, illustrates that something of this magnitude has to be a mandate or it is not likely to be readily assumed by most state and local governments and facilities."

Similarly, Illinois began a review of state provisions, but reported that "when [the MHSA] was essentially never implemented . . . this review did not proceed any further." A different view was stated by an Oregon official "[i]n my opinion, it is neither necessary nor appropriate for Congress to direct the states concerning state laws regarding patients' rights and patient advocacy."

C. Changes state-by-state

This section details state law revisions since passage of the MHSA, which are of three types: full adoption of an MHSA-recognized right not previously granted clients in any form, partial adoption of an MHSA right not previously granted, and extension of a state consumer right toward MHSA standards. All these revisions are set forth below -- first the states with extensive changes (adopting or expanding eight or more rights as recommended by the MHSA), followed by states with less extensive revisions (five or fewer such changes).

Hawaii. Since the MHSA, it has fully adopted seven additional consumers' rights recommended in the MHSA; the rights to an individualized treatment plan[6] , nonparticipation in experimentation[7], confidentiality of records[8], access to records[9], access to an advocate[10] freedom from reprisal[11], and legal counsel's access to the consumer[12] . Hawaii has also expanded one MHSA-recommended right: a consumer's right to visitors unless he is considered dangerous[13] .

Kentucky. Eight changes have been made in its mental health code provisions since 1980. This state has fully adopted three recommended MHSA rights: a consumer's right to participate in

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planning treatment services[14], freedom from restraint or seclusion[15] and the right to confidentiality of records[16]. Kentucky also now provides recipients five additional rights representing partial adoptions of MHSA recommendations. Consumers now have a general right to informed consent for treatment, but their decisions may be overruled if no permanent side effects will result from the refused mode of treatment or if no less restrictive modes of treatment are available[17]. Consumers now may keep, maintain and use personal possessions and money[18] and may receive visitors[19]. They also have the right to assert grievances through habeas corpus[20]. Finally, former consumers may seek expungement of their records but are not explicitly guaranteed access to them[21].

Maryland. This state made nine changes in its consumer rights statutes since the MHSA, of which seven of these changes constitute full adoption of MHSA guidelines; the rights to treatment and least restriction of liberty[22], participation in planning treatment services[23], nonparticipation in experimentation[24], freedom from restraint or seclusion[25], confidentiality of records[26], access to records[27], and referral upon discharge[28]. Maryland has also partially adopted two rights recommended in the MHSA: the right to protection from harm and abuse[29] and confidentiality of records for former consumers[30].

Mississippi. This state has made ten changes affecting mental health consumers, of which four constitute full adoption of their MHSA counterparts: the rights to an individual treatment plan[31], consumer access to records[32], consumer access to an advocate[33], and referral upon discharge[34].

Four of Mississippi's consumers' rights revisions constitute partial adoption of MHSA guidelines: the rights to treatment best adapted to rendering further treatment unnecessary[35], to have his treatment plan reviewed with him[36], freedom from restraint[37], and to be informed of rights in writing at admission[38].

Mississippi has also expanded two previously existing rights provisions since passage of the MHSA. One ensures that patients' records are confidential and not merely unavailable to the general public for inspection[39]; and the other is a right that visits or calls with a personal physician, attorney or spiritual advisor now be unrestricted, and that other mail and telephone use is permissible if the medical welfare of the consumer is not harmed[40].

The following nine states have since 1980 adopted five or fewer additional rights recommended in the MHSA.

Arizona. This state now provides consumers with referrals upon discharge[41], constituting full adoption of an MHSA-recommended right.

California. It grants consumers four additional MHSA rights, one of which constitutes full adoption of an MHSA right not previously afforded consumers in this state -- access to records[42]. The three other changes are partial adoptions of MHSA rights: protection of the right of consumers to assert grievances through habeas corpus[43], a general right to counsel[44], and records access by former consumers[45].

Connecticut. It has fully adopted the right to referral upon discharge[46].

Florida. Four subsequent changes have been made, of which two are full adoptions of MHSA rights: the rights to treatment and least restriction of liberty[47] and to participation in planning treatment services[48]. The other two changes are partial adoptions -- consumers now are entitled to an individualized, written, (though not updated) treatment plan[49] and are entitled to seek post-discharge treatment from a professional or agency of choice[50].

Idaho. It has partially adopted one MHSA right -- consumers have the right of freedom from seclusion[51]. In addition, Idaho has expanded a previously adopted right. While previously, a facility could override a patient's right to refuse specific modes of treatment for good cause, now a facility may do so only if the patient is incapable of giving consent or in an emergency.[52].

Illinois. This state has since fully adopted one additional MHSA right -- the right to an individual treatment plan[53], and has expanded another MHSA right -- consumers are now to be informed of their rights in sign language if necessary[54].

Minnesota. It has fully adopted the right of consumer access to records[55]. Also, this state has partially adopted two other MHSA rights: Minnesota consumers now have a right to be informed of other rights at admission[56] and a general right to counsel[57]. Finally, Minnesota has expanded a patient's mail privileges to include the right to send and receive sealed mail unless restricted by the head of the facility[58].

Montana. This state has since 1980 partially adopted one MHSA right -- consumers now have the right to be informed of their rights at admission in writing[59].

Texas. It has since fully adopted four MHSA rights: the rights to treatment and least restriction of liberty[60] to participate in planning services[61], to nonparticipation in experimentation[62] and to a humane treatment environment[63]. This state has also partially adopted another MHSA right -- consumers now have the right to an individualized (though not written or periodically updated) treatment plan[64].

IV. Discussion

Several lessons may be learned from the state response to the MHSA. It is clear that eliminating the enforcement provisions from the MHSA severely limited its effect: Illinois, for example, abandoned its review of its statutes because of the MHSA amendment to be merely advisory. Moreover, some of the post-1980 state law revisions may have come about regardless of the MHSA: the comments of the Hawaii Department of Health and of the Texas Mental Health Association seem to indicate strong local support for these reforms independent of the MHSA.

Furthermore, the remarks of the Oregon official reflect some state concern with the central issue with which Congress was concerned -- at what level of government consumers' rights should be protected.

The limited state response to the MHSA Bill of Rights may not be due solely to its advisory nature. Even mandatory Federal laws in other fields, attempting to require changes in state statutes or social welfare progams, have not always been followed by the expected changes. And even the provision of Federal funding tied to compliance with detailed specific requirements may do no more than produce short-term, superficial, results. For example, such is the opinion on many observors about the history of the implementation of a predecessor of the MHSA, the Federal Community Mental Health Centers program, where many believe that the statute not only failed to produce the results expected, but may well have been harmful.[65] Among other examples in recent years of the phenomenon of state failure to follow Federal statutory requirements are laws with the objectives of creating jobs for the hard-core unemployed, building new towns, and getting teachers to act differently. Bardach concluded that "the character and degree of many implementation programs are inherently unpredictable. Even the most robust policy . . . will tend to go awry. The classic symptoms of underperformance, delay, and escalating costs are bound to appear."[66]

The MHSA Bill of Rights was nevertheless important as a step in legitimating the very idea of rights for those who receive mental health services, and its content may have had influence on practice, legal advice, regulations, or court decisions, even if not incorporated in state statutes.[67]

Our study shows that while Congress deferred to the states to allow them primacy on revision of consumers' rights, most state legislatures have not taken up the invitation to review their laws to bring them up to the Federal standards.

One may recall an analogy from another, unrelated, field. When the Supreme Court initially recognized that individuals' search and seizure rights were applicable against the states, it was reluctant to invoke federal power, instead intimating the hope that states would reconsider their own rules.[68] About half--but only half--did so, and the Court thereafter imposed a mandatory requirement that states enforce the rights.[69]

V. Conclusions

This study has tested the relationship between one legal change (the MHSA Bill of Rights) and another (state law revisions) and has found the effect to be limited. We have not carried out any measurements of changes in mental health service practices in regard to patients' rights, though our estimate from informal observation and study of reports of service programs is that the changes since 1980 are not large. At the same time, we believe that the attitude of concern with patients' rights among professionals and the public is much greater now than it was a few years ago. Considering these three types of variables--legal changes, changes in practice among service agencies, and development of concern for rights-- the likely causal relationships are interactive. While the legal change, the MHSA, may have influenced attitudes and practices as well as influencing other laws, the changing attitudes themselves helped bring about the MHSA itself, as well as influencing the other legal changes reported here, and whatever changes in practice have occurred.

Table II

Post-1980 State Law Revisions Adopting Mental Health Systems Act Rights.

MHSA § 501	ARIZONA	CALIFORNIA	CONNECTICUT	FLORIDA	HAWAII	IDAHO	ILLINOIS	KENTUCKY	MARYLAND	MINNESOTA	MISSISSIPPI	MONTANA	TEXAS	TOTALS
(1)(A) Treatment and least restriction of liberty	N	N	N	A	N	N	N	N	A	N	P	N	A	4
(1)(B) Individual treatment plan	N	N	N	P	A	N	A	N	N	N	A	N	P	5
(1)(C) Planning participation	N	N	N	A	N	N	N	A	A	N	P	N	A	4
(1)(C) Explanation														
(1)(D) Right to refuse treatment	N	N	N	N	N	E	N	P	N	N	N	N	N	2
(1)(E) Nonparticipation in experimentation	N	N	N	N	A	N	N	N	A	N	N	N	A	3
(1)(F) Restraint or seclusion	N	N	N	N	N	P	N	A	A	N	P	N	N	4
(1)(G) Humane treatment environment	N	N	N	N	N	N	N	P	P	N	N	N	A	3
(1)(H) Confidentiality of records	N	N	N	N	A	N	N	A	A	N	E	N	N	4
(1)(I) Access to records	N	A	N	N	A	N	N	N	A	A	A	N	N	5
(1)(J) Converse privately, telephone, mail & visitors	N	N	N	N	E	N	N	P	N	E	E	N	N	4

TABLE II, continues

	ARIZONA	CALIFORNIA	CONNECTICUT	FLORIDA	HAWAII	IDAHO	ILLINOIS	KENTUCKY	MARYLAND	MINNESOTA	MISSISSIPPI	MONTANA	TEXAS	TOTALS
(1)(K) Information re: rights	N	N	N	N	N	N	E	N	N	P	P	P	N	4
(1)(L) Assert grievances	N	P	N	N	N	N	N	P	N	N	N	N	N	2
(1)(L) Fair grievance procedure	N	N	N	N	N	N	N	N	N	N	N	N	N	0
(1)(M) Access to advocate	N	P	N	N	A	N	N	N	N	P	A	N	N	4
(1)(N) Freedom from reprisal	N	N	N	N	A	N	N	N	N	N	N	N	N	1
(1)(O) Referral upon discharge	A	N	A	P	N	N	N	N	A	N	A	N	N	5
(2)(B) Confidentiality of records on discharge	N	P	N	N	N	N	N	P	A	N	N	N	N	3
(3)(C) Access by legal representative	N	N	N	N	A	N	N	N	N	N	N	N	N	1
TOTALS	1	4	1	4	8	2	2	8	9	4	10	1	5	59

A-Post-1980 adoption of MHSA right

P-Post-1980 partial adoption of MHSA right

E-Post-1980 expansion of existing law to more fully adopt MHSA right

N-No post-1980 action

(Note: TABLES III and IV were retained in the files of the Committee.)

FOOTNOTES

1. Mental Health Systems Act of 1980, Pub. L. No. 97-35, §501, 95 Stat. 357 (1981). *See generally,* H.A. Foley & S.S. Sharfstein, Madness and Government: Who Cares for the Mentally Ill 118-34 (1983).
2. President's Commission on Mental Health. *Report to the President*. Vol. I. Washington, D.C.: U.S. Government Printing Office.
3. Omnibus Budget Reconciliation Act of 1981, P.L. 97-35, 95 Stat. 357.
4. 126 Cong. Rec. S.9729, 9736 (Sen. Morgan); S.9730 (Sen. Hatch); S.9735 (Sen. Danforth); S.9736 (Sen. Javits); S.9744 (Sen. Roth).
5. Lyon, Levine and Zusman, *Patients' Bills of Rights: A Survey of State Statutes*, 6 Ment. Dis. L. Rep. 178 (1982).
6. Hawaii Rev. Stat. §334E-2(a)(7) (1984).
7. Hawaii Rev. Stat. §334E-2(a)(10) (1984).
8. Hawaii Rev. Stat. §334E-2(a)(14) (1984).
9. Hawaii Rev. Stat. §334E-2(a)(15) (1984).
10. Hawaii Rev. Stat. §334E-2(a)(21) (1984).
11. Hawaii Rev. Stat. §334E-2(a)(3) (1984).
12. Hawaii Rev. Stat. §334E-2(a)(21) (1984).
13. *Id*.
14. Ky. Rev. Stat. §202A.191(1)(a), (b) (1982).
15. Ky. Rev. Stat. §202A.191(1)(h) (1982).
16. Ky. Rev. Stat. §202A.091 (1982).

17. Ky. Rev. Stat. §202A.191(1)(c), 202A.196 (1982).
18. Ky. Rev. Stat. §202A.191(1)(d) (1982).
19. Ky. Rev. Stat. §202A.191(1)(e) (1982).
20. Ky. Rev. Stat. §202A.151 (1982).
21. Ky. Rev. Stat. §202A.091 (1982).
22. Md. Ann. Code H.G. §10-701(c)(1) (1983).
23. Md. Ann. Code H.G. §10-706(c) (1983).
24. Md. Ann. Code H.G. §10-707 (1983).
25. Md. Ann. Code H.G. §10-701(c)(3) (1983).
26. Md. Ann. Code H.G. §10-701(d) (1983).
27. Md. Ann. Code H.G. §10-701(d)(3) (1983).
28. Md. Ann. Code H.G. §10-708 (1983).
29. Md. Ann. Code H.G. §10-701(c)(4) (1983).
30. Md. Ann. Code H.G. §10-712(c) (1983).
31. Miss. Code Ann. §41-21-102(b) (1984).
32. Miss. Code Ann. §41-21-102(7) (1984).
33. Miss. Code Ann. §41-21-102(2), (5) (1984).
34. Miss. Code Ann. §41-21-82 (1984).
35. Miss. Code Ann. §41-21-102(b) (1984).
36. Id.
37. Miss. Code Ann. §41-21-102(1) (1984).
38. Miss. Code Ann. §41-21-102(9) (1984).
39. Miss. Code Ann. §41-21-97 (1984).
40. Miss. Code Ann. §41-21-101 (1984).
41. Ariz. Rev. Stat. Ann. §36-543(a) (1983).
42. Cal. Health & Safety Code §25250(6a) (1981).
43. Cal. Welf. & Inst. Code §5424.1 (1982).

44. Cal. Welf. & Inst. Code §§5325(h), 5326 (1963).

45. Cal. Health & Safety Code §25252(a) (1981).

46. Conn. General Stat. §17-206c (1982).

47. Fla. Stat. Ann. §394.453(1) (1982).

48. Fla. Stat. Ann. §394.459(2)(e) (1982).

49. *Id*.

50. Fla. Stat. Ann. §394.459(14) (1982).

51. Idaho Code §66-345 (1981).

52. Idaho Code §66-346(c) (1981).

53. Ill. Ann. Stat. 91 1/2 ¶3-209 (1981).

54. Ill. Ann. Stat. 91 1/2 ¶3-205 (1982).

55. Minn. Stat. Ann. §253B.03(2) (1982).

56. Minn. Stat. Ann. §253B.03(10) (1982).

57. Minn. Stat. Ann. §253B.03 (1982).

58. Minn. Stat. Ann. §253B.03(2) (1982).

59. Mont. Code Ann. §53-21-114 (1983).

60. Tex. Mental Health Code Ann. 92 §5547-80(b)(1) (1983).

61. Tex. Mental Health Code Ann. 92 §5547-80(b)(4) (1983).

62. Tex. Mental Health Code Ann. 92 §5547-80(b)(3) (1983).

63. Tex. Mental Health Code Ann. 92 §5547-80(b)(5) (1983).

64. Tex. Mental Health Code Ann. 92 §5547-80(b)(4) (1983).

65. Kubie, *Pitfalls of Community Psychiatry*, 18 Arch. Gen. Psychiat. 257 (1971); Kubie, *The Retreat from Patients*, 24 Arch. Gen. Psychiat. 98 (1971); Kety, *From Rationalization to Reason*, 131 Am. J. Psychiat. 957 (1974); Arnhoff, *Social Consequences of Policy Toward Mental Illness*, 188 Science 1277 (1975).

66. E. Bardach, The Implementation Game: What Happens After a Bill Becomes Law 5 (1977).

67. Letter from Leslie J. Scallet (formerly attorney with the Mental Health Law Project) on file with the U.S.C. Law Center

68. Wolf v. Colorado, 328 U.S. 25 (1949).

69. Mapp v. Ohio, 367 U.S. 643 (1961).

Senator **Weicker**. Thank you very much.

[The subcommittee adjourned at 1 p.m.]

○

S. Hrg. 99-50, Pt. 2

CARE OF INSTITUTIONALIZED MENTALLY DISABLED PERSONS

JOINT HEARINGS

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON
LABOR AND HUMAN RESOURCES

AND THE

SUBCOMMITTEE ON LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

OF THE

COMMITTEE ON APPROPRIATIONS
UNITED STATES SENATE

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FIRST SESSION

ON

EXAMINING THE ISSUES RELATED TO THE CARE AND TREATMENT OF THE NATION'S INSTITUTIONALIZED MENTALLY DISABLED PERSONS

APRIL 1-3, 1985

PART 2

APPENDIX: STAFF REPORT ON THE INSTITUTIONALIZED MENTALLY DISABLED

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APPENDIX

STAFF REPORT ON THE INSTITUTIONALIZED MENTALLY DISABLED

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STAFF REPORT ON THE INSTITUTIONALIZED MENTALLY DISABLED
REQUESTED BY SENATOR LOWELL P. WEICKER, JR.

Prepared for Joint Hearings Conducted by the

Subcommittee on the Handicapped
Committee on Labor and Human Resources

and the

Subcommittee on Labor, Health and Human Services,
Education and Related Agencies
Committee on Appropriations

April 1-3, 1985

Executive Summary

On too many wards of state facilities for the mentally disabled, residents and staff exist in a climate of fear and intimidation. And despite the regular outside scrutiny of, at best, only a handful of state-paid monitors -- whose internal reporting, however aggressive, is largely denied public airing -- these residents and employees live and work in virtual secrecy.

Conditions in many of these facilities, especially psychiatric hospitals, where some of society's most severely disabled patients live in a volatile daily mix with some of the health-care profession's most undertrained staff, would be considered intolerable if this airing was full and frequent.

Senate staff has found that on many wards, patients and residents are vulnerable to abuse and serious physical injury. Documented incidents in facilities visited by the staff include kicking or otherwise striking patients, sexual advances and rape, verbal threats of injury and other forms of intimidation. Milder forms of verbal harassment are seen as an important method for controlling potentially violent or aggressive patients and residents.

Another frequent method of control is restraint and/or seclusion. Patients of state facilities for the mentally ill and residents of state institutions for the mentally retarded are frequently subject to periods of forced isolation as a method to control behavior. A wide variety of mechanical restraints are also available to staff, designed to prevent injuries. Especially with highly agitated psychiatric patients, these restraint procedures are often dangerous tests of strength and the episodes are openly feared by staff and patients alike.

There is little treatment other than medication provided in many state institutions according to staff, patients and advocates interviewed by Senate staff. The great majority of state psychiatric patients on all wards visited by Senate staff are given some form of medication, many on an "as needed" basis as determined by direct-care staff. The general lack of activity tolerated in many state institutions visited by Senate staff leaves the ward dayrooms as the focus of patient and staff activity. Medications and mechanical restraints are often the only alternative or backup in direct-care staff attempts to maintain control.

Where injuries are reported, staff injury rates are generally higher than those of patients. The direct-care staff see their injuries as a product of low staffing, new and tougher patients, and lack of off-ward activities.

Many facilities visited by Senate staff fail to maintain decent living conditions. Many wards sleep patients/residents in long dormitories in beds several feet apart. As many as half the patients in some wards have no closet or private storage space. Lack of privacy in toilet and shower areas is often due to poor repair, with doors and curtains removed. Some facilities have no apparent internal standards, as several wards may appear barren and in disrepair with the smell of urine and cigarette smoke in the air and patients sleeping on bathroom floors, while another ward can appear clean and well-equipped, the patients engaged in minimal programming like exercise or discussing current events.

State systems for monitoring facility compliance with patient rights and seeking improvement of conditions vary widely. Federal funding for the protection and advocacy of mentally ill persons was once authorized by Congress (as it has been for the mentally retarded). But that authorization, along with an enforceable bill of rights for the mentally ill, was repealed by subsequent legislation.

Many of the nation's state psychiatric facilities are voluntarily subject to review by the private Joint Commission on Accreditation of Hospitals (JCAH). These reviews, which are frequently a determining factor in whether federal funds may be received by a facility with a passing grade, are an uncertain test of a facility's level of care and treatment of the mentally ill. Largely focused on paperwork requirements, the JCAH reviews occur at regularly scheduled intervals and are considered predictable by hospital personnel.

Psychiatric facilities participating in the Medicare and Medicaid programs are subject to review by the Health Care Financing Administration (HCFA) of the Department of Health and Human Services (HHS). There are a number of weaknesses in this process with the potential to adversely affect patient health and safety. States largely certify their own eligibility for federal money, subject to infrequent audits by the Health Care Financing Administration. When deficiencies are found, there are no federally-mandated deadlines for correction. A facility able to demonstrate progress toward correcting deficiencies is rarely decertified, even if agreed-upon deadlines are not met.

While the federal government spends approximately $2.5 billion on institutions for the mentally retarded and has established a comprehensive certification process to ensure compliance with over 600 standards, many residents of these institutions do not receive, in some cases, even minimal services and care. As in participating psychiatric facilities, states largely certify their own institutions for the mentally retarded, subject to a federal "look-behind" audit. But these audits are infrequent and more importantly, do not ensure timely correction of policy or practice when deficiencies are identified. Neither does the certification process address the issue of institutional residents appropriate for community placement. There is no formal or informal mechanism by which the Department of Health and Human Services and the Department of Justice share information, coordinate activities, or make referrals, although the agencies have clearly complementary responsibilities under federal law.

The U.S. Department of Justice continues to play a limited role in monitoring conditions in facilities for the mentally disabled as they relate to constitutional and federal statutory requirements. The few investigations commenced by the Department's Office of Civil Rights suggests a continuation of the inactivity noted in previous congressional testimony. Further, recently concluded investigations show that the Department's notice to the states as to findings have been sent up to 27 months after the investigations were initiated. The Department's lack of timeliness and consistently conciliatory approach in the face of conditions determined to be egregious and flagrant abuses of the institutionalized mentally disabled, allows these conditions to fester, distorting the purpose of congressionally mandated intervention.

State hospital admissions are no longer decreasing nationwide, partially because the population at risk for certain psychiatric disorders is on the rise. At a time when outpatient alternatives are overburdened and underfunded, the stage is set for a new era of institutionalization and an even greater role for hospital wards.

The findings of this investigation demand change. Abuse and neglect of society's most vulnerable citizens must stop. Care and treatment must be provided in an atmosphere of dignity and respect. And those to whom this care is entrusted must be held fully accountable.

Introduction

Over the course of several months, Senate staff travelled to 12 states and examined documents and interviewed individuals from several other states regarding environmental conditions and physical health and safety in state mental hospitals and, to a lesser extent, state facilities for the mentally retarded.

As part of this review, Senate staff visited 31 facilities and conducted an estimated 600 interviews with staff, patients of state psychiatric facilities and residents of state facilities for the mentally retarded, facility administrators, state and federal officials and others in the field.

Senate staff visited four institutions under confidential arrangements. These institutions are not identified in this report. However, additional formal and informal Senate staff visits were conducted in the following states and facilities:

CALIFORNIA

Camarillo State Hospital
Fairview State Hospital
Metropolitan State Hospital
Napa State Hospital

COLORADO

Fort Logan Mental Health Center

CONNECTICUT

Connecticut Valley Hospital
Fairfield Hills Hospital
Mansfield Training School
Southbury Training School

GEORGIA

Central State Hospital
Southwestern State Hospital

a) Thomasville Campus
b) Bainbridge Campus

MARYLAND

Springfield Hospital Center
Spring Grove State Hospital

MICHIGAN

Northville Regional Psychiatric Hospital
Ypsilanti Regional Psychiatric Hospital

NEW JERSEY

Trenton Psychiatric Hospital

NEW YORK

Creedmoor Psychiatric Center
Manhattan Psychiatric Center
South Beach Psychiatric Center

PENNSYLVANIA

Polk Development Center
Pennhurst State School
Embreeville Center
Woodhaven Center

TEXAS

Austin State Hospital
Terrell State Hospital

WASHINGTON (Day Treatment Center and Shelter)

Harborview Community Mental Health Center
Downtown Emergency Service Center

In the state psychiatric hospitals visited by Senate staff, the scene was generally the same:

Walking through a series of locked doors onto any of several adult psychiatric wards, the odor of cigarette smoke is pervasive and the stench of urine is often present, as is the television noise from a morning game show, afternoon soap opera or evening sitcom. A new visitor is quickly surrounded by a group of patients with the ever-present questions: "Are you a lawyer? Can you get my doctor? Can you get me out of here? Do you have a cigarette?"

Other patients shuffle away from the commotion, across a dayroom where patients and staff spend most of their days and evenings.

Most patients sit or lay quietly on available surfaces: furniture, including tables, radiator shrouds, window sills and the floor. Some sleep, some stare, others rock steadily in place or pick invisible nits from their hair.

Many patients look fleshy and unkempt, their clothing ill fitting and mismatched. Several talk to themselves, some try to draw others into their delusions forcefully, some protect invisible space around them by cursing at fellow-patient intruders who pace the dayroom continuously end to end. Most sleep or sit quietly.

The glassed gazebo jutting from a wall near the center of the room by a locked door leading to the dormitories, is a nurse's station. Inside, a nurse and/or aide is invariably filling out paperwork.

One wall of the station is papered with directives and policies from the facility administration and state central office. Another has a locked cabinet of medications and shelf of thick notebooks, one for each patient on the ward.

Another staff person sits with patients at the television, identified only by the keys on his belt and occasional commands to the pacers to move from the line of vision. Another staff person may be the fourth in a gin rummy game with a group of the "higher functioning" patients while at the same time, he consoles a patient with delusional fears who has pulled a chair up next to his.

If these four staff members are lucky, on a psychiatric ward they will have no more than 30 patients in their charge. If they are not, they may have 40 patients. Even in that former, relatively fortunate 7.5-1 ratio, any one of more than a dozen routine responsibilities can pull staff off of regular ward work on a given shift, instantly shifting ratios to 10-1, 15-1 or worse.

Violence is considered a de facto feature of ward life in many facilities, ascribed by staff to the aggressive nature of patients and residents, and by advocates to the lack of training of staff. Although sustained physical abuse of patients/residents has occurred in some facilities and patient-to-patient aggression is considered common, most staff-to-patient physical contact is a matter of ward procedure.

Many patients have PRN prescriptions for psychotropic medication, from the Latin "pro re nata" meaning "as needed". This "need" is often determined by ward staff observations of patients in agitated states. By some estimates, up to two in five patients on medication are subject to an involuntary movement disorder that can be permanent. The disorder, Tardive Dyskinesia, is poorly understood and infrequently monitored.

While these prescriptions are written in advance, other methods of control such as restraint and seclusion of patients can be initiated by ward staff and later approved by physicians. Some monitors have found a link between sudden death of patients and restraint procedures that often involve tying patients to beds in isolation rooms. The level of force required in these procedures varies, but patients and advocates complain consistently that excessive force is often used. Suspected rapes and beatings are reported during and subsequent to the use of these procedures.

Some facilities report a high percentage of unexplained injuries to patients, and Senate staff observed patients with unexplained bruises and cuts and patients seeking protection from other patients.

To avoid more intrusive procedures, ward staff frequently threaten patients with isolation or loss of privileges.

While facilities seek to maintain control, they frequently fail to maintain the basic amenities expected as part of their custodial function. Patients are often lined up and showered in succession on schedule, sometimes under gang showers without curtains or changing areas. Hand towels, soap and toilet paper can be missing from some ward bathrooms for several days, but plentiful on another ward of the same facility. Some patients sleep in a gymnasium with beds less than three feet apart, others live in dormitories where the lack of closet space forces them to keep their few belongings folded in a paper sack under their bed, at the risk of being stolen by other patients.

When asked, facility administrators and state officials say living conditions are in the process of being corrected. Ward staff, however, take a cynical view of these "plans". In several cases, ward staff said newspaper and television news accounts of these living conditions result in improvements, albeit temporary.

Although there is a general ethic against patient abuse as they narrowly define it, there is a palpable fear among staff on many wards. While most long time staff say the "old days" of staff violence against patients are gone, staff say they are seeing a younger, more aggressive patient, quicker to "go off" and tougher to "take down".

In this atmosphere, the complaints of staff are seen as weights on a scale that tip the delicate ward balance against them: irrelevant paperwork that takes time away from patient interaction; foreign-born doctors who hold broad commitment and medication authority, who rarely interact with patients and who sometimes have an almost tragicomic inability to deal professionally in the English language; a legal system that seems to encourage patients to file complaints against staff and discourage patients from taking medication; and most often heard, staffing ratios that are too low or assignments that "float" unfamiliar staff together on each shift.

From the patient's perspective, that balance is supposed to be maintained by internal monitoring and investigation of complaints by ombudsmen or patient advocates in the facility's employ. Only a few states provide for outside counsel.

Every hospital has a mechanism for reporting abuse and other incidents on the wards and most have designated employees to act on complaints and report to the facility administration.

But as with any hospital procedure, the policy is only as good as the numbers, authority and ability of those charged with carrying it out.

Residents of facilities for the mentally retarded hold a clear advantage over the institutionalized mentally ill in the area of advocacy to insure their basic civil rights. The federal government has a major role in this advocacy through the funding of Protection and Advocacy agencies in each state. In addition, if the residents are eligible for Medicaid funding the institutions where they live are subject to a certification review by state officials and a potential audit by federal officials from the Department of Health and Human Services.

But these audits are rare and the certification process essentially asks a state to determine its own eligibility for federal money.

In state psychiatric facilities, however, the advocacy process is wholly dependent on state initiative. Congress passed a law in 1980 authorizing funding for advocacy of state mental patients' rights and delineating those rights, but the law was repealed at the time of passage of the Alcohol, Drug Abuse and Mental Health block grant.

Many state hospitals submit to voluntary review by a private accrediting commission that largely bases a passing grade on the hospital's ability to show acceptable paperwork every three years.

In psychiatric hospitals, only persons below the age of 22 and over the age of 64 are eligible for federal Medicaid assistance. Facilities with these populations are also subject to state self-certification reviews. Only five percent of the facilities receive federal "look-behind" audits of these reviews.

The U.S. Justice Department has the authority under the Civil Rights of Institutionalized Persons Act to investigate potentially "egregious and flagrant" violations of the Constitution in facilities for the mentally disabled. Since the law was passed in 1980, however, only 24 investigations have commenced and one lawsuit filed; that occurred in February, 1985.

This combination of federal inaction has left protection and advocacy services for the mentally ill to a patchwork of state and volunteer monitors that vary widely in ability and authority. In one state, volunteers drive hundreds of miles a month to visit institutions and assess such conditions as cleanliness of the wards and the appearance of residents. In another state, highly-trained investigators conduct regular, systematic, often unannounced reviews of patient and resident care as an independent state agency.

Many states employ staff designated as patient ombudsmen who report to a state central office or the facility administrators. As advocates, these employees are generally designated to respond to specific complaints by patients and staff and have no charge to examine the broad range of patient care issues.

But as a practical matter, even these limited investigations of complaints about abuse or other violence, privileges, property, and other non-medical issues, involve these advocates in a strenuous, often adversarial process. Even a successful conclusion to an investigation of one violent incident involves only that incident and does little to address the conditions that make these incidents frequent on many wards.

Too often those whose professional responsibilities and personal efforts include attempts to lessen violence on wards work in virtual isolation. They are feared and disliked by ward staff, intimidated or ignored by the administration and work with law enforcement officials in a shaky, if existent, relationship.

A final inhibitor to violence in many facilities is the media. Accounts of conditions in facilities for the mentally disabled are a staple of investigative reporting in many parts of the country. Staff, patients, advocates and consumer groups frequently have come to rely on exposes in the media to prod state officials to make changes.

Other forces of change are also having a major impact in psychiatric facilities. Young adults of the so-called baby boom generation are now at the age of highest risk for onset of psychiatric disorders. A high proportion of the homeless are of this generation and considered mentally ill. Indeed, a major focus of the current debate over homelessness involves the proper "mix" of psychiatric care needed, including institutionalization.

The "asylum" movement that pleaded forcefully for custodial care of the mentally ill in the last century has adherents in modified form today. There is a growing call to loosen the standards under which the mentally ill can be involuntarily committed.

Whatever the outcome of this medical, legal and political debate, the fact remains that the census of state psychiatric hospitals is rising again. Predictions are made that the future population of inpatients could rise appreciably in the absence of alternatives, especially in state hospitals for those unable to pay for private care.

Physical abuse of patients and residents in some state facilities for the mentally disabled is a shocking reality. But a more significant reality is that this physical abuse is much less an impulse behavior of ward staff than it is a tragic outcome of ward routines. In their design, these routines are meant to protect patients. In their implementation, they often merely subject patients to situations that should not be tolerated.

The Institution

As a follow-up to a previous review of conditions in Intermediate Care Facilities for the Mentally Retarded (ICFs/MR), Senate staff was asked by United States Senator Lowell Weicker, Jr., to examine issues in state facilities for the mentally disabled, especially psychiatric institutions, that relate to physical health and safety in the facilities and further, to examine mechanisms in place to monitor and prevent institutional abuse and neglect.

Information in the public domain and obtained by Senate staff shows that no level of the current monitoring "system" insures the administration of basic justice, let alone quality care in many institutions for the mentally disabled.

In late September, 1984, a series of allegations of abuse was reported to the Division of Mental Health Advocacy, Department of the Public Advocate, State of New Jersey concerning Trenton Psychiatric Hospital.

The allegations, contained in affidavits, include multiple assaults against patients, including slapping, punching, choking to the point of semi-conciousness, hair-pulling and throwing of patients; verbal threats of severe bodily injury; repeated verbal abuse (i.e. "faggots, creeps, punks"); and excessive force when applying restraints.

The most serious of the allegations concerned a hospital staff member who has since been transferred to another unit. A hospital official told Senate staff the employee had been transferred because "these wild accusations" were making the employee's job difficult. He said such allegations were frequent and he called patient legal advocates "a disruptive force" at the hospital. One unit of the hospital has denied these state advocates access to ward areas and patient records that detail violent incidents on the wards.

Senate staff also heard allegations that deceptive procedures were employed by hospital officials in the facility's successful effort recently to obtain accreditation by the Joint Commission on Accreditation of Hospitals.

Hospital personnel have alleged a systematic moving of patients off the grounds of the hospital and to unseen areas of the hospital to keep the high level of inactivity from the eyes of reviewers. They further allege that individual patient charts were removed from nurses' stations so as to be unavailable for review. Other staff were allegedly ordered to begin impromptu, unprecedented "classes" on certain wards for patients, but actually for the benefit of reviewers.

Senate staff has also obtained copies of New Jersey's own periodic medical review for the hospital. This review is a self-certification to receive Medicaid funds. In the 1983 review, a state panel found nursing services at the hospital "totally non-complaint in the implementation of the medical regimen."

In the 1984 review, the panel states "nursing services have deteriorated to such a degree that care does not meet minimally accepted standards."

An investigation by a team of reporters during 1984 published in the Santa Fe (NM) Reporter, revealed a number of allegations, including the following, concerning New Mexico State Hospital at Las Vegas.

--An elderly woman died in July 1984 after part of a temperature-measuring device was allegedly left in her rectum by mistake, blocking her bowel movements; when it was finally removed, she went into shock and died shortly afterward.

--A 63-year-old woman died in February 1984 of "pneumonia," after threatening to commit suicide by self-induced vomiting. Before the fatal incident, she had been placed in seclusion in an unpadded room and had thrown herself against the walls. Upon viewing the body, her son said: "It was real sloppy care. Mom had bruises all over her face."

--In several cases, "pneumonia" was listed as the cause of death of patients who allegedly had gastric tubes slip from their stomachs into their lungs due to negligent care. Other patients who died of "pneumonia" had been left in cold rooms with windows open and inadequate bedcovers. In the words of one nurse: "They are dying of exposure."

--Despite their right to have professional witnesses in their behalf, only 12 of the last 3,000 people committed to the state hospital have had such witnesses.

--An audit in 1984 revealed that more than 10 percent of the hospital's current psychiatric patients did not have up-to-date legal papers authorizing their commitment.

--Beginning in 1979 and continuing to last summer, state officials received numerous reports of abuse at the hospital from individual staff members, groups of staff, anonymous sources, and two special investigators. The reporters documented that in each month of 1984 through August, state officials learned in increasing detail of abuse and neglect in the facility through internal investigations and clinical audit. In August, the reporters interviewed the state's top health official and apprised him of their findings. The state then initiated its first official, public investigation of the hospital. The head of the state-appointed panel defended his decision not to "name names" or otherwise assess blame for deficiencies found in the 12-day investigation: "Do you think it's easy for me to write this kind of report? I, too, feel deep concerns about the hospital, but is was also important for us to keep our credibility in the government."

In February, 1981, a deaf-mute patient at Northville Regional Psychiatric Center in Michigan died, apparently strangled, while being restrained. A nurse had reported the patient "acting up" and aides converged on the man to strip him in preparation for being placed in seclusion. During this procedure he was given an injection of medication and later found dead. State police investigation results were turned over to prosecutors, who denied warrants on criminal charges. Several aides were referred for counseling and further training in physical restraint. The nurse was allowed to resign.

The death was one of a series of unexplained or suspicious deaths or suicides revealed in a copyrighted report by the Detroit News following a three month investigation in 1982-1983.

In April 1981, a patient died while in a coma following an escape attempt. Several weeks earlier, the patient had been found in a Northville seclusion room, lying in a pool of blood. The patient's father visited his son at the hospital and told the News, "He had a lot of cuts on his face and a tooth was missing. I don't see how he could get a lot of cuts in a hospital seclusion cell. He told me he was beaten up. He was really frightened. He said they were going to kill him." Two hospital direct-care workers named in the incident were fired but later reinstated. "This is frustrating to everyone," the state's mental health director told the News. "One of the problems throughout the system is the ability to develop a case that will stand the test of arbitration hearings and the due process issue."

In July 1981, a patient died while in a coma after being placed in seclusion. The patient's attorney told the News an autopsy concluded the cause of death was strangulation, noting throat marks and bruises "indicating excessive force had been used in restraining" the patient.

The state police has reportedly investigated more than 40 suspected rapes at Northville since 1981. One aide has been convicted of three rapes and jailed, but police say "99 percent" of the cases involve patient-to-patient contact.

On Nov. 15, 1982, the U.S. Justice Department began a formal investigation of Northville.

In November 1984, Senate staff observed basement areas of the hospital accessible to patients where staff-to-patient and patient-to-patient sexual contact has been documented and reported to authorities. State investigators said prostitution in return for minor personal items and amounts of money has occurred.

Senate staff also observed a "blind spot" on one ward where two suicide attempts have been made since December 1983. Despite reports to hospital officials, no correction was made.

Staff and administration alike openly consider their facility as the dumping ground for Detroit's most aggressive and difficult young patients.

The hospital has no official capacity and as a result, some 30 people a night sleep in the hospital gymnasium. Some wards sleep patients in dayrooms and beds have sometimes been placed in halls. The overcrowding sustains a high level of tension and staff say PRN, "as needed" medications are used frequently to control patients.

Senate staff observed instances of 25-1 staffing on adult male wards. In two cases, Senate staff observed patients in dayrooms maintaining a "vigil" behind a large table, kept there, said the aide in charge of the area, to protect them from beatings by other patients.

Hospital personnel on one ward insisted Senate staff privately view a young patient who "doesn't belong here." The man had serious difficulty walking and using his arms. His head remained cocked and his voice was loud and incoherent. "One of the doctors said he's got cerebral palsy," a ward staff member said. The patient had several bruises and recent cuts on his face, head and arms. The staff said the patient was frequently beaten on the ward because "he can't get out of the way of other patients fast enough."

On one ward, a charge aide in her forties who was one of two staff for 35 male patients on the day shift, spoke to Senate staff of her fear on the ward. She said there was nothing for the patients to do and not enough staff. She complained that the inactivity made the men restless and that the medications were not powerful enough. She said the staff had nicknamed the ward "Dodge City."

In February, 1985, the Justice Department notified the state of its findings of conditions that "threaten the health and safety of patients." The notification further stated that "our attorneys will be contacting your office shortly to discuss this matter further."

A 35-year-old female patient in a locked, all-female ward at South Carolina State Hospital suffered a fatal seizure between 3 and 4 p.m. January 15, 1984. At the time of her death she had lain tied to a bed in full restraint for 13 hours and her clothing was soaked with her own urine.

An autopsy later revealed traces of substances found in semen in her vagina and pubic hairs that were not hers in her restraining suit. Technicians determined the patient may not have been given her regular anti-seizure medication while in restraint. Last August, 11 indictments were handed up against current and former employees of the hospital on charges of patient abuse and neglect. Four of the indictments were related to the above case, two related to the accidental choking death of a patient, and four to an alleged beating of a patient.

In November, 1984, the results of a U.S. Justice Department investigation were made public by the State Department of Mental Health. Justice found serious deficiencies in the number of qualified physicians and nurses, insufficient safety procedures for dangerous patients, inadequately trained doctors, questionable drug prescriptions and improper restraints.

The U.S. attorney for South Carolina said the Justice investigation began in October 1983 after an unnamed citizen complained of abuse at the state hospital adolescent unit. Eight months previous to that, the state had been sued by a group of adolescents whose allegations included reports of patients made to lay in their own feces in restraint for up to three days. The suit was filed as three separate investigations by state agencies were underway and a month after the unit's director had been fired.

South Carolina Senator Arthur Ravenel, R-Charleston, told Senate staff he "had to beg Brad Reynolds for a year" to involve the Justice Department in the South Carolina situation. Ravenel said Justice Department attorneys seemed "afraid of their boss", Reynolds. After months of attempting to contact Reynolds, Ravenel called Senator Strom Thurmond, R-South Carolina. "Then we got some action," Ravenel said.

The foregoing graphic examples represent elements of a pervasive lack of accountability observed by Senate staff in facilities for the mentally disabled throughout the United States.

Over a period of six months, staff was invited to visit a number of facilities and requested access to many others. In no case was a request denied, but on several occasions, access to certain areas of a facility was not allowed.

Many invitations to visit were issued on an unofficial basis and only after a guarantee that Senate staff would keep confidential the facility name and the names of all persons interviewed. The invitations came from various groups and individuals, including a superintendent of a state hospital; the administrator of a facility for the mentally retarded; professional staff; direct-care staff; advocates, and family and friends of patients and residents.

During these visits, Senate staff attempted to gain the broadest access possible to the facilities. This access varied from several wards over a period of three hours to one ward for five days.

The nature and specificity of the information obtained was also varied. After consulting with a group that regularly monitors conditions at both facilities for the mentally ill and facilities for the mentally retarded, Senate staff adopted elements of facility monitoring forms used by citizen advisory boards in two states. In these states, the boards use formal questionnaires to assess a variety of conditions on selected wards. The conditions include the type and appearance of patient/resident clothing, the availability of toilet articles, linens and personal effects, the type of restraint and seclusion of patients/residents in use during the visit, the general condition of furniture, toilets, showers and sinks, and the type of activity in which the patients/residents and staff are engaged. By using these forms in wards of several facilities, Senate staff gained an understanding of the elementary physical concerns of institutional life.

Further perspectives were gained during visits to wards hosted by advocates, lawyers and professional monitors. Senate staff accompanied many of these individuals on "rounds" of facilities to note their perspective on their mission and the authority behind their jobs.

Psychiatrists, psychologists, social workers and other professionals, including administrators and their staffs, also conducted tours and gave information on institutional problems and potentials from their point of view.

Senate staff also conducted interviews with patients of psychiatric facilities, residents of institutions for the mentally retarded and representatives of consumer organizations composed of ex-patients and residents. Senate staff attempted to observe whatever "programming," "training," "rehabilitation," or "treatment" available.

By far, the greatest amount of time was spent on the wards of psychiatric facilities interviewing and observing patients and direct-care staff, to whom the mission of the facility is largely left to accomplish.

The Ward Perspective

Direct-care personnel observed and interviewed by Senate staff in psychiatric facilities make very frank assessments of patients' conditions on the ward. Certain patients are described as "burnouts," generally older patients who behave in a way so as to demand very little interaction with staff. Younger patients who exhibit the same quiet and solitary behavior on the ward seem to earn a different reaction from the staff. These patients are generally closer in age to the young 20-30-year-old staff and the reaction is more one of curiosity, sometimes wonderment that such a condition should exist in a person so young. For these patients, staff can frequently cite a personal history, including a key event that caused the patient to "check out" of society.

Still another group of patients is verbal, physically active within the confines of the ward and anxious and insistent in their interactions with staff. The direct-care staff was frequently heard describing these patients as "high," or "nuts". These patients, on many wards, create a constant hum of voices, punctuated by shouts and accusations, and a regular stream of movement. To a certain level, the activity is allowed by the staff, many of whom feel they have an understanding of behaviors considered routine versus those behaviors that could be disruptive.

Patients considered at risk of suicide, escape, acts of violence or those in restraints or some type of seclusion are frequently placed on "close observation" or "one-on-one." In these situations, which generally must be approved by a doctor, staff members must maintain an arms length or line-of-sight distance from a patient 24 hours a day until the order is lifted. While the staff member is so occupied, he or she is unavailable for regular ward duties. Senate staff has observed wards where these situations have created 20-1, 25-1 ratios of patients to available staff. The latter ratio occurred in a Michigan hospital, where Senate staff observed the single direct-care worker offering cigarettes to one patient in exchange for the patient's help in keeping other patients "cool."

Some staff members at a psychiatric facility in Ohio reportedly try to stay near groups of "friendly" patients as a shield against more aggressive patients. (1)

The staff's sense of being outnumbered and anxious is common on wards visited by Senate staff. Further, there is a sense on the wards that direct-care workers are facing the patients alone. Often, their only real backup is psychotropic medication or mechanical restraints.

Aside from their own classifications of patients' behavior, the direct-care staff generally has spotty knowledge and little need to understand various psychiatric diagnoses. And aside from entering personal observations in patient charts at the end of shifts, direct care staff have little incentive beyond curiosity to understand the work of the medical staff.

There is a high degree of cynicism expressed by direct-care staff in many facilities concerning the work of some medical, legal and administrative staff. This is especially true of the staff's view of institutional psychiatrists. These psychiatrists, many of whom are foreign medical graduates, are thought by many direct-care workers to have taken institutional jobs because they are unqualified for other psychiatric work. In one hospital visited by Senate staff, the staff psychiatrists had limited licenses, which permitted them to practice only in the institution.

Echoing the comments of other institutional staff, including psychiatrists, the direct-care workers say there is virtually no psychotherapy at state psychiatric facilities. Instead, Senate staff commonly heard institutional psychiatrists referred to as "gatekeepers," whose medical licenses enable them to approve medications and procedures used to handle problem patients, such as restraint and seclusion, and ultimately decide on a patient's release. These issues are also reflected in public accounts of institutional care.

Officials in the Missouri mental health system told the Kansas City Star that foreign medical graduates are a problem in a state where 68 percent of the state's doctors hold degrees from foreign schools.

"'This just drives me crazy,' said William Taylor, chairman of the state's Mental Health Commission, which oversees the department. 'About every time I (go to a state hospital) I meet a doctor I can't understand. It's a big problem. It's scary.'" A superintendent of one of the state hospitals, himself a foreign medical graduate, recalled his own language problem: "'When I started my residency in Topeka, a paranoid woman was talking to me. She was talking about her husband stepping out on her. I thought he must have been a crazy man, stepping on her toes.'" The newspaper reported that, "Several persons familiar with the state's mental health system have similar concerns about such doctors treating disoriented patients with whom communication is difficult." (2)

A former state hospital patient in Michigan, where 55 percent of the state doctors are foreign born, related his experience with a foreign medical graduate to the Ann Arbor News. "'You can't talk to them. If they don't know what you're talking about, they think you're crazy,' he said. In answer to one of his doctor's questions, he talked about a friend's father's trip to China. Later, she asked him about his own father, who is dead. On his chart, the doctor wrote: 'Patient thinks father has been in China and is deceased at the same time,' according to the patient who saw the chart." The president of the state psychiatric society told the newspaper, "'Now we're left with a profoundly disturbed nucleus of patients and a reduced nursing staff. It's difficult to recruit physicians.'" (3)

In late 1983, 21 of the 25 full-time psychiatrists in Kentucky's state hospital system were foreign medical graduates. In a series of reports in the Louisville Courier-Journal, hospital administrators praised the abilities of the foreign-trained doctors. But Dr. Edward Tyler, medical director of the state's largest community mental health center, complained of the physicians' treatment methods. "Rather than trying to talk out a patient's problems in therapy, Tyler said, some foreign doctors prefer to control the patient's psychosis through medication. Often that is because the foreign physicians are uneasy dealing with American attitudes, Tyler said. 'We've swung heavily into prescribing pharmaceutical agents rather than trying to help the person adapt to life,' said Tyler..." (4)

Conversely, a California state hospital that maintains a unit for Spanish-speaking patients, employs a Spanish-speaking direct-care and nursing staff on the unit, but has been unable to recruit Spanish-speaking doctors away from better-paying private sector jobs. Staff on the unit said interaction between patients and physicians occurs through translation.

One analysis suggests that, "For a number of years academic training programs have placed a low priority on the treatment of the chronically mentally ill, who constitute the majority of public patients and who do not traditionally respond to insight-oriented psychotherapy." (5)

Perhaps because there appears to be so little psychotherapy in many state institutions, the lack of fluency in English and understanding of American culture on the part of many of the psychiatrists is not considered a critical situation by direct-care staff. Instead, it is often a source of coffee-break and lunchroom humor: a patient who responded "cool" when asked how he felt began receiving more blankets; a patient who said he had previously worked in a kennel was described as believing he had lived with dogs in a tunnel; a black patient with his hair fixed in braids called "corn rows," was described as exhibiting feminine characteristics; a doctor told a patient there were no trains nearby after the patient said he had been "railroaded" into the hospital.

Variations of these and other language and cultural barriers were heard at several facilities. Clinical directors at two facilities told Senate staff they felt there is a "trend" in the psychiatric profession toward institutional work that is bringing many more American graduates to the facilities. Although this may remedy one area of the direct-care staff's concern, the more significant area of concern involves the lack of regular interaction between psychiatrists and the direct-care staff and psychiatrists and the patients.

Relations between the direct-care staff and other medical professions at the facilities vary widely. On many wards, licensed practical or vocational nurses handle many of the same tasks as the direct-care staff, who are variously classed as mental health workers, mental health aides, residential care aides, psychiatric technicians, etc. Some states continue to allow certain grades of direct-care staff to dispense some medications and the confusion of responsibilities is noted as a source of tension between staff.

Many wards or groups of wards are supervised by registered nurses, a profession that administrators generally acknowledged as in perpetually short supply at many of the facilities visited by Senate staff. The RN's interviewed by Senate staff complain uniformly that they are forced both by regulations and lack of staff to "treat paper, not people." The nurses said as much as half their time on the wards is spent completing paperwork and that the bulk of their supervisory time is used to ensure that staff adequately documents ward activity for administrators and surveyors. As supervisors, the RNs are frequently expected to assign janitorial chores to direct-care staff. These truly "custodial" chores are a further source of tension between staff.

Psychologists, social workers and various occupational, rehabilitation and activity therapists are considered by direct-care staff to be genuine allies in the care of the patients. Although each of the occupations is seen as in short supply in the facilities, their interactions with patients are generally seen as valuable to the custodial and therapeutic functions of the ward.

Psychologists are seen as providing a socializing function to the patients, providing an outlet for aggression and the tools for interacting with staff and the other patients. Social workers provide the link between the patients and the "free world," as the outside is often called. Social workers' involvement with patients' families and alternative placements and programs are thought to give patients a reason to act appropriately and eventually leave the institution. Therapists, when available, are valued for the "break" they give direct-care staff in the daily involvement with patients. The activities they provide are considered enjoyable by most patients and often require the kind of concerted effort with its attendant rewards that is missing in daily ward life.

To the extent that each of these functions are in place and regularly available, direct-care staff can sense the fit between their function and the therapeutic goal. Aside from the obvious courage and tenacity exhibited by many of these employees, Senate staff observed regularly the work of direct-care workers who were eager to play a therapeutic role.

Psychiatric patients who exhibited distress or fear on wards visited by Senate staff were sometimes calmed and soothed by ward staff. Many staff members take special pride in their experience and ability to cheer up or "talk down" patients without training of any kind.

Had it not been for one direct-care worker in New York, a man who had been institutionalized most of his life might still be living in a locked shower room, naked, with a single sheet to cover himself. After the staff member threatened to sue the institution on behalf of this resident, services and treatment were provided which have helped him learn to feed and clothe himself; attend day treatment off the institution grounds; and to live, under supervision, with a group of other disabled adults.

In one facility for the mentally retarded, a group of direct-care workers decided that the absence of trained therapists was resulting in some residents losing the ability to hold objects in their hands. The workers developed their own "course" of exercises designed to retain and develop the residents' ability.

Despite the persistence of dedicated individuals, the numbers continue to work against them.

The lack of adequate staff is perhaps the most consistent complaint of existing personnel, cutting across the lines of diagnosis of patients/residents or the various levels of accreditation achieved by a particular unit.

In three separate institutions for the mentally retarded including the one just mentioned where employees designed the training course, staff were observed feeding residents who were capable of feeding themselves, albeit at a slower pace.

The problem pointed out by staff in each of the cases was the lack of adequate personnel to take this slower pace into account at mealtime. That is, the number of residents per staff, combined with the amount of time available for a particular meal, meant the residents could not be afforded the chance to use self-feeding skills. Instead, the facility staff lifted spoonfuls of food to the residents' mouth as the preceding mouthful was swallowed.

Another area of staff shortages noted consistently by facility staff concerns staff levels on geriatric wards. Senate staff were told by professionals and other supervisory personnel on wards for the aged mentally disabled that the census of these groups is rising in state facilities, presenting ever-greater challenges to staff, especially in nursing care.

Doctors said the medical profile of long-term geriatric patients, especially those in psychiatric facilities, is increasingly similar to nursing home patients. They noted the increase in neurological disorders, frequently Alzheimer's Disease, that bring with them increased behavioral and control problems to the wards.

The head nurse on one geriatric ward in Connecticut told Senate staff the daily routine of feeding, dressing and cleaning her patients left the staff no time for such activity as helping patients retain the ability to feed, dress and walk themselves.

On one geriatric ward in Michigan, Senate staff observed approximately 25 men sitting and/or sleeping quietly in chairs lining a dayroom. Two of the men cradled toy animals in their arms. In one corner, by the television set, a direct-care worker sat watching, with her arm around a man apparently talking to himself. "They're being good today," she said.

Findings

Senate staff requested a variety of institutional data from approximately half of the institutions visited. (Data was not requested from institutions when Senate staff did not announce their visits or when Senate staff toured a facility with an advocate not employed by the facility.)

A review of the data Senate staff did receive showed vast differences in recordkeeping. As a result, a comparison, and in some cases even a simple evaluation, of data was virtually impossible.

However, the data received did reveal that: On many wards, patients/residents are vulnerable to abuse and serious physical injury.

All of the institutions responding to a request for information documented incidents of patient abuse within the last year which resulted in disciplinary action against staff. The majority of these institutions fired at least one employee. Some employees were allowed to resign with termination charges pending.

Two facilities fired as many as six staff members in 1984 for documented incidents of patient abuse. At one facility, where five people where fired, two staff persons were fired for kicking a patient; two were fired for hitting a patient; and one person was fired for administering an improper injection which resulted in injury to the patient. At another facility, one staff member was fired, and another was removed from the ward, for improper sexual advances toward a patient.

In December 1984, a staff member at a Connecticut hospital was fired for striking a patient who was in restraints. The employee's union decided to grieve the firing formally at which point, the hospital had to call in authorities for an investigation. The union had agreed to sponsor the grievance because employee witnesses had denied the abuse occurred. Before the investigation began, however, the witnesses acknowledged the abuse and the grievance was dropped.

Union contracts and protections often make it impossible for hospital administrators to actually fire an employee. In lieu of termination an employee may be suspended, demoted, assigned to another unit, or otherwise reprimanded.

During Senate staff visits, hospital administrators frequently expressed frustration with grievance procedures which prohibit employee termination or allow employees to be reinstated after they have been fired. Administrators said they seek to ensure employees a fair hearing and opportunity to respond to hospital allegations, but Senate staff was told of numerous instances of plea bargaining and reduced sanctions even when abuse has been documented. Senate staff was also told that, in one California jurisdiction, it is virtually impossible to get the local district attorney to file criminal charges in substantiated rape allegations if the rape involved a psychiatric patient, whether victim or suspect.

Senate staff was told that patient abuse is far more frequent than the number of incidents actually reported. At one hospital, a nurse told a Senate staff member that she had specifically requested a transfer to a particular unit where she knew patients were being abused and staff was not reporting it. This nurse has a reputation for reporting abuse and often fears staff retaliation for such action. As a result, the nurse varies her route home to avoid being followed and having her residence identified.

Despite official expectations and no matter how conscientious the direct-care staff, it is unrealistic to expect that staff abuse can be adequately monitored and disciplined by relying on fellow workers as the primary reporters. Aside from strong personal considerations, including loss of effective working relationships and documented threats of retaliation, there are institutional barriers to this sort of freelance monitoring.

During one in-service training session for staff at a facility for the mentally retarded, a staff development officer told the group that the institution "is very strict about abuse." Attending the session was a group of new and longtime staff members. One of the veteran direct-care employees interrupted the session to warn the group that reporting staff abuse of residents could be a difficult undertaking.

"You've got to be two people," the staff member said. "Otherwise you don't have a leg to stand on."

The staff development officer answered that, whether two people witnessed an incident or not, individuals must report abuse to their supervisors.

But the staff member continued: "Hey, live and learn. I went through it. You do your job and then you're a heel. It's not worth it. I reported it and they said, 'hey, you've got to be two people."

A programming aide at one state hospital (sometime also called a therapist or teacher) told Senate staff she has little faith in the abuse reporting procedures: "(When I see abuse occur) I know I have recourse, I know I can tell my supervisor, and I know I can write a report and try to get a witness to go along with me, but in reality I don't think there is anything that will be done...because of the union being so strong and because I don't think that it is important to the administration. I don't think they really care, unless there's some physical abuse where someone is hurt and their reputation might be at stake. I don't think verbal abuse matters."

Senate staff met with institution monitors and advocates who have observed and reported client abuse. During a visit to an institution for the mentally retarded, one advocate told a Senate staff member she had observed a direct care worker "snatch" a client by the hair, "fling" him into a chair, and "jump" on him to hold him. Earlier that day, the same advocate had observed a direct care worker push the same client across the room into the steel springs of a bed frame. Senate staff later observed this client, naked in a room furnished only with a metal bed frame with wire springs.

In addition to the documented incidents of physical abuse of patients in institutions, many patients suffer serious injuries from other causes.

In some cases, serious injuries to patients have been sustained with no cause reported. At two facilities for the mentally retarded in Connecticut, a third of the serious resident injuries in a one-year period, were reported as having no known cause. Serious injury at these institutions is defined as resulting in fracture, hospitalization, and/or death. In more than half of the serious resident injuries sustained at one Connecticut facility, it was determined that no one was at fault. At one state hospital in Georgia there were 506 patient injuries last year for which the cause was unknown. One hundred seventy-seven of these injuries required attention by the hospital Medical/Surgical unit.

Most hospitals keep extensive records on patient injuries. Some include patient injuries as part of a comprehensive annual incident report; some hospitals note the injuries in individual patient charts; and still others categorize injuries in such a general manner that neither the cause nor extent is discernible.

For those hospitals that clearly document the causes of patient injuries, the number and nature of these injuries reflect an environment which threatens the safety of hospital residents.

Patient-to-patient assaults are a common cause of injury. At one state hospital in California 46 percent of all patient injuries were caused by aggressive acts between patients. At two other hospitals visited, a third of all patient injuries were caused by other patients.

Senate staff consistently observed cuts and bruises on patients and residents that facility staff explained as patient-to-patient injury.

Another explanation given for observed cuts and bruises was patient self-abuse. Senate staff observed patients and residents who deliberately tried to harm themselves either by intense scratching at parts of the skin, or banging their heads against a wall until facility staff intervened.

In one hospital, Senate staff was told of a patient who had deliberately run, twice, head first, into a hospital wall. The patient subsequently died from the injury.

On a "behavior-modification" unit of a Pennsylvania facility for the mentally retarded, several adolescent and young adult males were observed with reddened and marked faces, arms and hands. Scabs were visible and some of the residents continually fingered or picked at the scabs. A direct-care worker observing these residents called their names and the action caused them to stop briefly. The worker said the residents were "self-stimming," or stimulating themselves, and said the aim of the unit was to stop this behavior.

On the same unit, a resident with similar markings was observed in a seclusion room. Outside the door, a staff member observed the resident through a small porthole and timed the 15-minute seclusion period. Inside, the resident was observed scraping his head back and forth across a heavy-gauge window screen, his head bloodied. Following the prescribed seclusion period, the resident was removed to the dispensary for brief medical treatment. Staff members said behaviors such as self-abuse, aggression towards staff, urinating and defecating on the floors, and destruction of property, were common on the unit. "They do it to get attention and it works," said one staff member. Two additional rooms on the unit are being converted to seclusion areas, Senate staff was told.

In many of the hospitals Senate staff visited, dormitory and bedroom areas are opened earlier in the evening than hospital policy dictates in order to reduce and minimize tension and aggression on the unit. One unit staff member told Senate staff that the time after dinner and before evening medication can be a particularly "high" or volatile time on the unit. Allowing the patients to move from the crowded hallways and dayroom helps dispel the potential for patient violence and injury.

Another method observed and reported to minimize violence and potential injuries is a separate "secure unit" for the more violent patients. Senate staff visited secure units during their site visits and noted a growing trend toward creating such units. On one secure unit, hospital police are called in to walk through the unit when staff determines there is a dangerously-high potential for violence.

Suicide attempts, Senate staff was told, are considered common in any state institution.

Despite the installation of mirrors, breakaway shower-curtain rods and other ward alterations, there is little confidence that suicide can be prevented. Most wards do not have a full set of any physical barriers to prevent suicide and instead rely on physician orders for constant observation of a patient considered at risk for suicide.

Hospital staff are also at risk of serious physical injury. Last fall, a direct-care worker at a California hospital died following an assault by a patient. After being struck by the patient, the employee fell and suffered a fatal blow to the head. Senate staff visited the facility a short time later and spent an afternoon on a unit where, the previous evening, a hospital staff member had been repeatedly beaten in the head by a patient. A few days earlier, the director of a nearby hospital told Senate staff that violence is the ticket for the mentally ill to be admitted to a state hospital. An official of the union that represents psychiatric technicians (direct-care workers) in the state, said that, at any given time, approximately one in 10 of the technicians is off the job due to a patient-related injury.

Assaults by patients on hospital staff are a fact of ward life in many states. In 1984, 65 percent of all staff injuries at one Connecticut hospital were the result of assaultive behavior by patients. More than half of the 486 staff injuries last year at a Michigan hospital were patient related and approximately one-third of the job injuries reported to the hospital infirmary at one New Jersey hospital were injuries sustained from patient assaults.

While no national figures are available to determine the relative risks of direct-care work, the employees' fear of injury in psychiatric facilities is high. For these employees there is often little more than their own wits or physical abilities to get them safely through the dangerous situations they could face on a given shift on a given ward.

Few direct-care staff said they had been given training in either psychiatric or physical intervention techniques, although such courses exist in some hospitals.

At one hospital, Senate staff attended a three-day course required of all new employees involving a variety of "non-violent" physical techniques for subduing and/or restraining violent patients. The instructor began by stressing that the basis of the techniques was an attitude that the ward staff is supposed to defuse confrontation, not participate. The staff was warned that looking into the eyes of a psychiatric patient could be considered threatening as could a display of tension or fear on the face or body of the staff member.

The physical interventions include a series of blocks, reversals, take-downs, escorts and emergency and restraint procedures. Each of the interventions requires a technique that goes beyond simply learning the physical moves. Blows from patients are supposed to be met with open palms and crossed forearms and deflected; the ward staff was then to back away. Getting a patient to the floor was to be accomplished by sliding the patient's body down the leg of the staff member to a sitting position. For "escorting" or moving a recalcitrant if not violent patient, the direct-care workers were not to grip the patient, as this is considered confrontational. Instead, the technique calls for keeping the thumb locked against the index finger as you escort the patient, instead of opposing as in a grip.

The instructor said that, above all, ward staff was not to react to patient aggression in kind because it was both illegal and unnecessary. For situations where the staff member's life was in jeopardy, the class was taught in a five-minute demonstration how to jab fingers onto the patients carotid artery to cause a momentary blackout.

On a ward of the same hospital, Senate staff interviewed direct-care workers at length about the non-violent training. Although many praised the facility's effort to provide training, each described in detail situations in their experience that made non-violent interventions impossible.

First, the patient's violence was frequently swift, without warning and seemingly unprovoked. Such acts as punches to the head or blows from behind required the staff to immediately go to the highest level of intervention available. One staff member said "you grab anything you can (on the patient) and hold on," hoping that a nurse would respond quickly with an injection or enough staff would be available to help tie a patient in restraints. Even if the less violent interventions are learned well, there is seldom a chance to practice.

One charge aide supervisor on an adult psychiatric ward in Michigan called it the "code of the west." She explained that "taking a patient down" during an aggressive outburst meant punching or kicking when necessary. Such excessive force is never reported by staff, she said, and is denied if patient complaints lead to an investigation.

In addition to the lack of adequate numbers of personnel to deal with violent situations, there were complaints about the lack of the right kinds of staff. In the lexicon of skills that direct-care workers prize in their colleagues, the highest appears to be the courage to help a fellow worker in a violent confrontation with patients. A second seems to be generally the ability to "read" a patient and determine when the patient is ready to "go off," or "go high."

But the direct-care workers in many facilities say these skills are rated low by the hospital administration. Several hospitals visited by Senate staff routinely move direct-care workers off regularly assigned wards to fill in for absentees. The workers said this "floating" can create a ripple effect of tension, both on the worker's regular and newly-assigned wards. The workers also said the hospital as an organization fails to recognize what the workers believe is the proper mix of male and female staff on the wards. The workers say patients are more easily "talked down" by staff members of the opposite sex and that each ward needs a set percentage of male staff on each shift for violent situations. Forms of intimidation - considered "verbal prompting," but often harsh and threatening - are often used in violent situations and when assembling some patients for medication or meals.

Many hospital staff do not take any breaks during their shift time for fear of leaving a unit short staffed and in potential jeopardy. Many hospital staff cite frequent and extended absences of hospital employees as a result of injuries sustained on the job.

The review panel formed by U.S. District Court Judge Barefoot Sanders to monitor the Texas mental health system pursuant to a lawsuit, said in 1983, "it is apparent that there is a large amount of violent behavior in the state hospitals."

Violence should be anticipated, the panel said, "because the state hospitals serve patients who become acutely disturbed because of psychoses or who have problems with anger, handling frustration or impulse control. It is the hospitals' responsibility to control the patients' behavior, in order to protect patients from themselves or others, to protect staff, and to provide treatment to reduce the causes of violent behavior. The use of psychotropic medications can be effective in reducing the acute agitation of psychosis, but social treatments are necessary to help patients become more socialized in dealing with anger and frustration, and in developing tolerance and impulse control."

The panel said that at six hospitals, "almost all of the staff's interventions around violent behavior are crisis-oriented and aimed at bringing an already volatile situation under control. They are therefore reactive rather than proactive and preventive in nature. There is little indication of attempting to develop a therapeutic environment which neither fosters or tolerates violent behavior; and there is little evidence of systematic therapeutic efforts to alter behavior patterns and re-socialize patients."

In its conclusion to the report, the panel said, "There is a general failure to provide individualized treatment programs, there is a high degree of violence among patients, and there is inadequate staffing in the hospitals. These issues appear to be very closely related. Where there is a lack of meaningful programming, there is likely to be higher incidence of unacceptable patient behavior. And where staff is being overwhelmed by the demands of keeping order, it is not surprising that treatment would be relegated to the format of large group programs aimed at the least common denominator in the group." (6)

One year later, after continued monitoring and court-ordered staffing and programming improvements, the panel reported to the court it was "pleased with the emphasis which is being placed upon rapid identification of, and interventions with the development of aggressive behavior."

The panel noted the importance of "structuring the environment to discourage the development of aggressive behavior" and further, wrote, "Several units have recognized that a staff person's fear for their own safety, or comfort or discomfort in handling an aggressive incident may influence the outcome of that incident. Some staff feel more threatened by aggressive acts than others and the way staff react to incidents can either exacerbate or calm the situation." (7)

A report issued last June by the Governor's Task Force on Health and Safety at Cleveland Psychiatric Institute, cited important "themes" and "impressions" that emerge from discussions with staff and patients:

> "The unsafe atmosphere of the hospital was a theme which appeared and reappeared during much of the Task Force's inquiry. Both patients and staff reported an atmosphere of tension, apprehension and concern for physical safety...An atmosphere of fear, tension, and a sense of futility in getting the sympathetic attention of administration, state officials and the media may make employees feel more like angry victims than health professionals...
>
> "Our impression from talking with staff, patients (and others) is that patient abuse by staff does occur with greater frequency than is reported. Possible causes cited were inexperience and poor training levels of some staff, inadequate screening of prospective employees, and a cautiousness or inability on the part of administration to adequately discipline or dismiss flagrant abusers, as well as the stresses of operating indefinitely under adverse and understaffed conditions...overall one got the feeling of apprehension and concern for safety. When staff themselves share such concerns, the impact on patients, already in an extremely vulnerable state, can be seen to be devastating." (8)

An official at a facility for the mentally retarded in Pennsylvania described the abuse reporting ethic at work there. Officials recently completed an undercover operation at the facility that led to staff members being charged with client abuse. The authorities were alerted only after one staff member related the allegations to the facility superintendent during a clandestine meeting after dark in the facility's parking lot.

In South Carolina, the state Legislative Audit Council has accused the South Carolina Mental Health Department of attempting to cover-up abuse allegations and death reports by failing to forward internal investigations to authorities in violation of state law.

Sufficient staffing, proper training, and frequent monitoring by patient advocates and representatives are all essential to enhancing abuse reporting and increasing prevention of abuse.

Clarence Sundram, Chairman of the New York State Commission on Quality of Care for the Mentally Disabled, has suggested basic strategies for preventing patient abuse that speak directly to the crucial role of direct-care staff.

1. "The task of prevention really begins...with increased attention to the critical role of direct care staff, who have the greatest hands-on contact with patients. Facilities must be allowed to more carefully screen applicants to detect their attitudes toward mentally disabled people and any personal qualities that are relevant to working in the

institutional environment.

2. Once staff are hired, they should be treated as the asset they are. A substantial share of the facility's education and training budget should be devoted to developing direct care employees through training in necessary job skills and in dealing with anger and stress. Emphasis should be placed on dealing with burnout, perhaps through professional conferences with other staff on work-related responsibilities. Employees assistance programs must be available at every institution. Overtime and double shifts should be avoided at all costs because of the toll they take on staff and patient alike.

3. Equally important, professional staff need to be regularly present and available on the wards beyond normal business hours. To reinforce supervisors' obligations toward preventive efforts, investigations of alleged abuse should closely scrutinize the supervisors' responsibility for conditions that may have caused or contributed to an abusive incident.

4. A concerted effort must be mad [illegible] recruit volunteers to assist staff, particularly during time of greatest pressure on staff energies.

5. Finally, careful consideration should be given to the kinds of staff members assigned to particularly troublesome

> wards, such as intensive treatment units for violent male patients."

"Better preventive efforts," Sundram writes, "if they successfully reduce abuse through peer pressure and change the attitudes of staff in state institutions, may lift the veil of secrecy from future incidents. The likelihood of such result will be significantly enhanced if methods are found to protect reporting sources from reprisals, for example, through reassignments of patients or staff, and if investigations and prosecutions are made more effective through the use of independent professional investigations and attorneys." (9)

Living conditions for patients/residents in many state institutions are unacceptable.

Senate staff visited both certified/uncertified and accredited/non-accredited institutions for the mentally disabled. visited accredited and non-accredited state hospitals for the mentally ill. Accreditation and certification standards and procedures are designed to ensure minimal levels of condition and treatment and are discussed at length in a later chapter of this report. However, it is important to note here, that, although certified and accredited facilities for the mentally disabled appear, in general, cleaner and more spacious than uncertified and non-accredited facilities, many of the following conditions were observed in both.

Dormitories and Dayrooms

Bed capacity is often exceeded in both accredited and non-accredited facilities.

At an accredited facility in New York, a unit with a supposed maximum capacity of 30 beds has, at times, accommodated up to 60 patients. At a non-accredited facility in Michigan, some units are so overcrowded they routinely "sleep off" a handful of patients. The patients selected to "sleep off" must either spend the night on another unit or sleep in the hospital gymnasium where beds are set up each night. During the day, dormitories are locked, forcing patients to congregate in the hallways and in the dayroom.

While certified facilities for the mentally retarded limit the number of residents per bedroom consistent with certification standards, non-certified buildings on the very same grounds often resemble the stark, overcrowded dormitories in the psychiatric hospitals. The director of a Connecticut facility described these differences as a "a dual system," which serves both the "haves" and "have nots".

Sleeping areas rarely contain private closet/storage space for each patient. In some facilities, staff explained that there were not enough wardrobes (unit of drawers, shelf and hanger space) available. On other wards, staff explained that sharing wardrobes was considered acceptable. No matter the number of wardrobes in a sleeping area, patient clothing or personal effects are generally not in evidence. In addition, there are rarely items of furniture beyond beds and wardrobes. Walls are generally bare.

Senate staff observed sleeping areas that accommodated from one to 40 beds and there is generally a relationship between the number of beds and the personalization of a sleeping area. The larger, unpartitioned sleeping areas are generally bare of decorative items or other personal touches. As the size of the area decreases, sometimes through the use of partitions, patients seem to have adopted certain spaces around their beds, with decorations or posters on the walls and more personal effects in the wardrobes. Areas that accommodate one to four persons are generally reserved for patients as an incentive or punishment for their behavior in the group. Several of the areas seemed fully personalized. Many had night tables, with reading lights and reading material.

A problem noted frequently by patients is the lack of adequate space and security for the personal items they do have. Some patients have locked wardrobes in the sleeping areas with one key each for patient and staff. Some wards have locked closets that are used to store patient items like money, cigarettes, coffee, special clothing, etc. Staff and patients on several wards said staff theft is an occasional problem. Senate staff observed patients at one hospital, on "grounds' pass" visits to a coffee shop, clothing store or recreation area, carrying shopping bags of personal items from their wards for safekeeping.

The use of partitions, often five-foot tall, modular walls, to individualize large sleeping areas is controversial. Advocates support the effect of creating smaller spaces, while staff are often critical, saying the partitions block the view of patients in bed. Senate staff observed areas in partitioned rooms where fires had been set by patients at night. While sleeping areas are generally locked during the day, this was especially true of partitioned areas. Patients, however, seemed to enjoy the effects of partitioned rooms. The dividers created more "corners" where patients could gain some measure of privacy. This is contrasted with the unpartitioned rooms, where sleeping or relaxing patients are often only inches away from others in a tight line of beds.

The largest area of the ward is generally the dayroom, where patients and staff pass the majority of their time. And passing time is generally an apt description of dayroom activities. The focus of the majority of dayrooms is the television, around which groups of patients and staff are often seen to congregate.

One direct-care staffer, describing dayroom "therapy," said, "We of the General Hospital provide The Guiding Light to The Young and Restless through The Edge of Night," referring to the soap operas that are standard dayroom fare. Most dayrooms lack reading material or board games, although some wards have table games such as ping-pong or pool. Despite the staff cynicism toward "television therapy," it was observed and referred to often as a companion of both patients and staff. Staff seems to value activities that concentrate patients' attention away from staff, away from other patients, and away from unseen, indecipherable impulses or feelings. Television removes the necessity of interaction, but engages patients who function on a variety of levels.

Few other dayroom activities can be so generalized on many wards, where lucid, calm and involved patients live with withdrawn patients or those who are periodically agitated or aggressive. Senate staff observed wards over a period of several days where highly agitated and delusional patients lived with patients admitted for substance abuse as part of their diagnosis and who had recently "binged" to the point of becoming a danger to themselves and/or others.

These latter patients sought out the direct-care staff for more individualized ward activities like card playing, pool or conversation. These activities were consistently interrupted by more "troubled," apparently lower functioning patients. On several occasions, the disruptions observed by Senate staff resulted in arguments between patients and once, a minor injury to one patient.

Direct-care staff were frequently heard to threaten patients with "time out," a form of seclusion behind an unlocked door, when the patients agitated behavior began to involve staff or other patients.

Mindful of this limited menu of activities the direct-care staff has in the dayroom of many facilities, there is a sort of logic behind the sight of patients in solitary activities like sleeping, smoking, pacing and watching television. From day to day, shift to shift, there are many more possible negative outcomes for staff if they attempt to interact with patients than there are positive outcomes. Personal staff attitudes aside, this is especially true of staff as employees in the hospital organization. There are few rewards in that organization for direct-care staff, whether they interact with patients or not. On the other hand, there are several possible punishments for improper interaction.

Showers and Bathrooms

Many of the shower facilities observed by Senate staff were group showers. Often these showers had no curtains to offer patients any privacy. When curtains were provided they were frequently dirty and moldy and badly in need of replacement.

On one unit in a California hospital, staff was shown a group shower but was told patients showered individually. In fact, hospital staff said it would be "barbaric" to ask patients to shower together. However, when Senate staff stayed on the ward to observe shower and medication time, all of the 12 women on the ward showered together.

In an accredited facility in New Jersey, Senate staff observed a shower located directly off the dayroom. Hospital staff indicated that a make-shift dressing area with sheets and partitions is erected at shower time.

Bathrooms frequently had no doors on the stalls and toilets that did not flush. These toilets were sometimes filled with feces, urine or vomit. In some hospitals, toilet paper is kept in dispensers in the bathroom. In other hospitals, patients must ask staff for toilet paper, sanitary napkins, and other toilet articles. Senate staff observed bathrooms where sinks were clogged or inoperable, urine was left on the floor and no soap or towels were available. On some units, bathrooms are locked and patients must ask staff for access. Direct-care staff frequently claim that patient behavior prevents the staff from keeping toiletries available.

Senate staff observed bathrooms and shower rooms with no hot water and some with no water at all. On one unit of a California hospital, patients told Senate staff there had not been hot water for days. Hospital staff admitted that this has been a recurrent problem. On another unit in the same hospital, there was hot water but no soap for the showers. Hospital staff said a new supply of soap would probably not arrive for at least a week.

Regulating room temperatures, as well as water temperatures, can also be a problem. Senate staff was told that the units at the California facility were so hot last summer that some patients were treated for heat stroke. Others were sprayed with water through plant sprayers to lower body temperatures.

Conversely, when Senate staff visited a New York psychiatric facility, one unit was so cold patients were not permitted to shower in the morning and wore coats all day on the unit. Hospital staff told Senate staff that cold indoor temperatures are a recurrent problem on winter days.

Senate staff was often told that the units they visited were roach infested. At one hospital in California, staff complained of fly infestation. One Senate staff member was told that when the units at a Connecticut facility were sprayed for roach control, the residents who were lying on the floor were also sprayed. Senate staff observed roaches in New York and Georgia hospitals.

Clothing

With a few exceptions, most of the institutions Senate staff visited provided the residents with state clothing. While some institutions obviously made efforts at individualizing clothing and keeping clothing separate from that of other residents, the majority of facilities stocked underwear, socks, bras, pants, shirts, dresses, etc. in bulk by size and distributed the clothing accordingly. Senate staff routinely observed residents in clothing that did not fit; clothing that was inappropriate for the time of day and season of the year; and clothing that was torn and soiled. Patients frequently claim their personal clothing, brought in by family and friends, never comes back from the laundry.

Dining Facilities and Meals

Meals in state institutions are provided both on and off residential wards. The abilities and special needs of the facility residents often dictate where and how meals are served. Some meals are served in a separate dining facility, cafeteria style, while others are served on individual trays in a dining area on the ward. Residents who are medically involved or physically disabled, were observed being fed in their rooms and in hallways.

Those who eat in a separate facility are usually accompanied by staff and closely supervised during mealtime. One or two staff members may be left on the unit with the patients/residents who are not ambulatory; who are at risk of running away; who are continually disruptive; or who are in restraint and/or seclusion. Individual meals are prepared and delivered for these residents upon request.

Senate staff visited wards where residents were never permitted off the ward. On one such ward, meals were delivered in large containers and apportioned according to the number of residents. Plastic spoons were the only utensils provided. "Seconds" were supposedly available if desired, but barely enough food had been delivered for everyone to eat once. Approximately three residents chose not to eat dinner that evening and their meals were offered to the other residents on a first come first serve basis. Mealtime on this unit of 43 men lasted 20 minutes.

Dining facilities off the unit were consistently large, noisy, and sparsely decorated. Senate staff did observe dining areas with tablecloths, and in one case plastic floral arrangements, but these areas were rare.

Mealtime at a Pennsylvania facility for the mentally retarded observed by Senate staff was designated for 5:30 p.m. on one ward. The food for the approximately 40 residents was wheeled through the dayroom on a cart into a locked dining area. At 4:40 p.m., a carton of milk, spoon and napkin were set at each place on the tables. Ward staff said they had assembled the residents in the dayroom for no particular activity but to wait for the evening meal. Through a window, residents could see the milk on the table and food in family-style aluminum serving trays on the cart. Several residents, appearing upset, attempted to enter the dining area and were physically moved back by the staff. At 5:30 p.m., the door was unlocked and the residents were admitted to eat. Eating with the residents, Senate staff found the food to be lukewarm and the milk barely cool. The facility staff supervisor said the meal is served daily at 5:30 no matter when the food arrives. At 6 p.m., before some residents had finished their meal, direct-care staff members began washing the tables with soap and water.

"We have suggested that they try having quieter meals, close the curtains, break up the tables for three or four clients each," said one patient advocate. "But the staff sees meals as a chore to be accomplished; something you have to do and get it over with. We could get a lot of interaction going during these meals."

Mealtime can be a particularly difficult time for direct care workers. Patients/residents must be closely observed while walking to the dining area as well as during mealtime. At one facility, rather than walk outside and risk a resident trying to escape, direct care workers escort patients through an underground maintenance area to the cafeteria. A minimum of two staff members walk with the patients, one in the front and one in the rear, to ensure that no residents try to hide in the tunnel; attack a staff member or resident; or harm themselves on the pipes exposed along the walls and ceilings.

Residents are closely watched during mealtime for potential disruptions and accidents. And accidents, at least at one hospital visited, are frequent. While Senate staff was observing lunchtime in a California hospital, a loud alarm sounded throughout the hospital grounds. Hospital staff told Senate staff that the alarm usually means someone is choking and needs assistance. The sounding of the alarm at lunchtime, hospital staff said, is not unusual.

At many of the institutions visited, Senate staff tasted the food. In the psychiatric hospitals the food was usually bland and starchy. Patients often complained of eating the same foods continually. In institutions for the mentally retarded, the food was frequently ground or pureed. On one unit, 33 of the 36 residents had their food ground. To the cook's knowledge, none of the residents were on any program to develop an ability to digest whole foods.

There is little treatment, other than medication, provided in many state institutions according to staff, patients and advocates interviewed by Senate staff.

While individual patient records may include extensive descriptions of treatment plans, Senate staff observed very little such treatment in the 31 facilities that were visited. This apparent lack of treatment was described by one facility director as "milieu therapy". When Senate staff asked for an example of milieu therapy, the director said that if it was not visible, then that was a sign it was working.

None of the other facilities Senate staff visited claimed to provide any similar invisible therapy. However, staff members and patients consistently said that therapy, other than medication, at their facility, was virtually non-existent.

At uncertified facilities, overcrowding, staff shortages, and unpredictable patient behavior are all common explanations for the lack of treatment. At many of the certified facilities Senate staff visited, hospital staff complained that they spent so much time developing and documenting treatment plans that it was practically impossible to implement them.

Most of the units Senate staff visited posted a chart of daily and weekly activities. These charts included times for meals, recreational activities, and group program and therapy sessions. Comparing what was scheduled with what was observed, however, revealed that watching television or sleeping was actually the activity that filled a majority of a patient's/resident's day.

For some patients, getting to therapy sessions, day programming or other off-ward activity is impossible. Some psychiatric hospitals operate on a level system that grades patients' ability to handle free time. While visiting a New Jersey hospital, Senate staff was told that if a patient was not on a level that allowed him or her to leave the ward, therapy or day programming was often unavailable. Often staff either could not or would not escort patients off the ward.

At some hospitals, even the most basic social training is not provided on the ward. On an adult male ward at a Michigan hospital, one entire dormitory was reserved for bed wetters. Hospital staff said that most, if not all, of the incontinence was a behavioral problem. However, to the direct-care staff's knowledge, no treatment programs had been developed for the behavior. The incontinent men, staff said, were grouped together for convenience purposes.

In one New York facility, a male resident who is dually diagnosed as mentally retarded and mentally ill, was observed in a seclusion room naked and screaming. Senate staff was told that no formal behavior modification plan has ever been developed for this 34-year-old man who came to the facility when he was 11 years old.

While some treatment plans are never developed and others are developed but never implemented, there is one consistent treatment activity: the dispensing of medications. In psychiatric hospitals, the call to "line up for meds" can usually be heard four times a day. Varying dosages of psychotropic medications such as Haldol, Thorazine, Mellaril and others are dispensed in liquid and pill form to a majority of the patients on a ward. The percentage of residents on psychotropic medications in institutions for the mentally retarded generally is less than those in institutions for the mentally ill. However, a significant number of developmentally disabled residents are on some form of anti-seizure medication.

Many psychiatric patients have PRN's in addition to the scheduled medications. PRN's are prescriptions for additional medication to be administered on an as needed basis. Like all medications, these prescriptions must be authorized by a physician. However, Senate staff visited hospital wards where every patient had a written PRN on file in the nurses' station. These PRNs are often used to help subdue assaultive patients.

Particularly in psychiatric institutions, control appears to be the treatment goal, and medication the chief method of achieving control.

Senate staff did not request or obtain access to patient/resident medical records in any facility. For reasons of confidentiality, these records, pertaining to prescription and application of medications, are considered highly sensitive and are available only to authorized personnel. In addition, review of these records requires the sort of individual patient assessments and sampling techniques not envisioned by this project.

Few organizations that monitor state facilities for the mentally disabled include regular, systematic monitoring of medications as part of their work, although medication practices are a major area of complaint of patient rights organizations and many patients and direct-care staff.

Medication in these state facilities is considered the principal discretionary function of physicians. The patient or advocate complaints that question the administration of medication, however, usually concern a specific drug or drugs and the dosages or side effects concerning a specific patient. Nursing staff concerns, told to Senate staff, involved such things as the "passing" of medication by untrained ward staff, the undermedication or overmedication of certain patients, the lack of adequate physician involvement, and the dangers of illegal drugs taken by some patients in combination with prescribed drugs.

Systematic review of medication procedures have revealed significant problems in New York psychiatric facilities, a state where the Commission on Quality of Care for the Mentally Disabled has substantial authority and expertise to monitor the broad spectrum of institutional issues. The Commission, in its recent review, found that "for 71 percent of the patients reviewed comprehensively documented annual physical exams were not available and that for 41 percent regular medication reviews had not been conducted. For more than 85 percent of the sample patients, medication changes had been ordered with no documented physician rationale, a deficiency which was compounded by the often multiple treating physicians involved with the care of these patients. Standing orders for PRN medications were present for nearly one-half of the sample patients, and, significantly, only 57 percent of these orders were usually accompanied by a documented physician rationale. None of the records of the sample patients who were being treated with multiple psychotherapeutic and anticonvulsant drugs, contrary to NYS Office of Mental Health polypharmacy guidelines, contained a documented physician rationale for the use of polypharmacy. Perhaps, most shockingly, fewer than 15 percent of the sample patient records contained required documentation for the quarterly monitoring of adverse side effects from their medications are required by the Office of Mental Health." (10)

This final point concerning side effects is especially pertinent when considering the adequacy of monitoring medication practices. An estimated 20 to 40 percent of patients taking neuroleptic drugs exhibit some form of Tardive Dyskinesia (TD), an involuntary, sometimes permanent, sometimes debilitating movement disorder. Senate staff observed several patients/residents exhibiting what appeared to be involuntary movement on wards of state hospitals and facilities for the mentally retarded.

Some ward staff, including nursing staff and physicians, said the movements were a symptom of the patient/residents' medical or developmental disorder. Three patients exhibiting the movements, when asked by Senate staff, said the movements were due to the medication and that their doctors were trying to stop the facial twitching, leg and hand shaking, or gnarling of fingers, by changing their drugs.

One recent article explored lawsuits by patients' families against physicians and warned of an "impending crisis in TD litigation."

The authors warned that "elements of clinical practice that have proven to be critical issues in the 14 cases known to us, and that may have prevented a settlement or a verdict against (the) physician, are still not routine elements of psychiatric care: these include conservative prescription of neuroleptics, informed consent, careful monitoring for early signs of dyskinesia, periodic neuroleptic withdrawals or dose reductions, documentation of positive neuroleptic effects, and skills in the diagnosis of TD.

"One is not being glib in averring that the 1980 American Psychiatric Association Tardive Dyskinesia Guidelines (American Psychiatric Association Task Force, 1979) are honored more in the breach than the keeping. In fact, a review of the history of TD demonstrates nothing as clearly as this disconcerting fact: since 1957, published guidelines, scientific articles, presentations at professional meetings, and draconian admonitions in the Physicians' Desk Reference seem to have had little, if any, effect on actual physician behavior with respect to neuroleptic drugs." (11)

Another method of control is the use of restraint and seclusion. Policies and procedures for using restraint and seclusion vary from one institution to another. The kind of restraints and seclusion used also varies.

During visits to institutions, Senate staff observed the use of leather restraints, padded restraints, camisoles and mittens. Patients/residents were observed walking on wards with their hands restrained, while others were observed with both their hands and ankles cuffed in leather restraints, or wrists and ankles restrained to a chair or bed.

In one facility, Senate staff observed a woman in 4 point restraint in a chair mounted to a wooden platform. Although the platform was in the middle of the dayroom, sheets were hung around the platform so the woman could not observe any part of the room.

In a certified institution for the mentally retarded, Senate staff observed one restraint chair bolted to the floor in the middle of a resident's room.

The most common observance of the use of restraint was restraint in beds. Senate staff observed residents who were restrained to a bed in three, four and five point restraints. (Five point restraint includes a restraint around the resident's waist). Sometimes the resident was face down. Other times the resident was on his or her back. The bed was usually, but not always, bolted to the floor in a seclusion room. In one facility, Senate staff member observed an adolescent in four point restraint lying on his back in a bed in the middle of a crowded unit hallway.

In one facility, a patient was observed restrained to a bed naked in three-point restraint, one at each wrist and one for both legs. (At other facilities, the leg restraint would be considered inadequate, as it could allow a patient to move his legs in unison, creating a rocking motion and a possible injury to the patient). After a direct-care worker discovered the patient had urinated in the bed, the sedated patient was walked through a patient area in leg hobbles to a shower.

As a procedure that often takes place at the peak of a violent episode, restraint of patients/residents is potentially dangerous for all involved. Direct-care staff cite numerous injuries to staff from these procedures. Several facilities have "panic buttons" used to summon staff from other wards to assist in restraining patients. Staff have said that the delay in getting help makes for longer periods of physical restraint -- staff holding patients on the floor -- before sufficient staff arrives to apply mechanical restraints.

One recent investigation of the death of a psychiatric patient during a restraint procedure found no wrongdoing on the part of staff, but said, "This case does present a disconcerting reality: that eight able-bodied men, trained in managing aggressive patients, had difficulty managing one out-of-control, delusional patient."

The investigation report included data concerning restraint and seclusion deaths in New York facilities between 1979 and 1982, which found that 19 patients in adult psychiatric centers died "during or subsequent to being secluded or restrained." Eighty-four percent of the patients were males and the average age was 32. Eighty eight percent of the deaths involved restraint only. (12)

Seclusion is often used without restraint. Assaultive patients who do not appear to intend to harm themselves are often placed in seclusion rooms without restraint. Seclusion rooms are usually empty or furnished with a mattress or bed. While seclusion rooms should always be free of debris and potentially dangerous items, Senate staff observed seclusion rooms where cups, tissues, sheets, etc., had not been removed after the room had been used. The cap of a hypodermic needle was found left on the floor in one seclusion room and, in another, a sharp piece of metal was found protruding from a window screen.

In certified institutions for the mentally retarded, the use of locked seclusion rooms is prohibited. "Time out" rooms have been designed, instead, to provide a secluded but unlocked place for a resident to be by him or herself. Some time out rooms can be locked but only with a hospital staff member pushing on a cross bar outside the room. This locking mechanism requires a staff member to be outside the room able to observe the resident through a window at all times.

Every institution Senate staff visited had written policies and procedures for the use of restraint and seclusion, as well as time out. These policies and procedures included observing the resident at set intervals of time and documenting each of these observations in the resident's chart. At most facilities, a physician must authorize the use of restraint and/or seclusion past a certain maximum length of time for each episode. In some facilities an extended use of restraint and/or seclusion requires the approval of a facility committee.

However, although staff are required to check and document the use of restraint and seclusion in short intervals of time, Senate staff observed residents in seclusion who, hospital staff informed them, had been in seclusion for several days. In one state hospital in California, a psychiatrist told Senate staff that some patients at his hospital have been in seclusion for several months.

Senate staff was also told that suicide attempts are not uncommon while patients are in seclusion.

In a report recently approved by the American Psychiatric Association Board of Trustees, the Task Force on the Psychiatric Uses of Seclusion and Restraint states, "Seclusion serves a legitimate and irreplaceable purpose on the modern inpatient ward." (13)

Monitoring

The Advocates

During institutional visits, Senate staff encountered many different kinds of advocates and systems to protect patients' rights. On most visits Senate staff met with the institutional employee who was designated as the "clients' rights advocate." The responsibilities and design of these offices differed from state to state. Some clients' rights advocates were full time; some were part time. Some investigated allegations of abuse, while others referred all allegations of abuse to a separate investigator. Some advocates consistently visited hospital units on "rounds" to converse with patients and ask about their concerns. Some were so inundated and short staffed they often struggled to catch up with weeks-old complaints patients had forwarded to their office.

In California, the office with the responsibility for handling patients rights in each institution is authorized by state statute. This patients' rights advocate reports to a supervisor in the central office of the State Department of Mental Health.

Each California institution is also required to have a special investigator on staff who is a sworn peace officer and who is solely responsible for investigating allegations of patient abuse and client deaths. The special investigator reports to the hospital director, who, in turn, makes all final determinations of abuse and adverse action. Similarly, at state schools and hospitals in Maryland complaints of abuse are reported to and investigated by the local police as well as by the hospital administrator and his or her staff.

While all of the institutions Senate staff visited had documented policies for reporting complaints and abuse, implementation of these policies was often impractical and ineffective.

In Texas, the Department of Mental Health and Mental Retardation has a pilot program in one state hospital for one internal patient rights advocate. The program comes complete with pages of procedure and the hospital has locked boxes into which patients may anonymously place written complaints. But the boxes are located in areas inaccessible to patients on locked wards. The alternative for these patients, the advocate told Senate staff, was to use pay telephones on the ward or tell ward staff. Both options have glaring disadvantages to complainants seeking privacy.

Michigan has boxes also, on each ward of one state hospital. Several times each week they are emptied by one of four employees of the state's Office of Recipient Rights, an advocacy agency. But in this hospital of some 1,000 patients, there are an average of 1,500 "incident" reports filed monthly and more than 200 complaints regarding abuse and other allegations of mistreatment. The office says it can investigate an average of 30 complaints a month.

In California, the patient complaint system on some wards relies on patients telephoning the patient representative from a pay telephone located on the unit. However, each unit, of approximately 30 residents, is allotted only $5.00 worth of dimes for telephone use each month. On the average, this limits each patient to less than two telephone calls per month.

Hospital staff say patients can and do ask the staff to contact the patient representative for them. Patients, however, told Senate staff that it was awkward, intimidating and rare for a patient to ask hospital staff to contact a patient representative so that her or she may file a complaint.

In New Mexico, a state hospital housing 600 patients, has one patient advocate, a long time employee and former hospital barber. Despite a substantial body of official documentation of physical violence, revealed by a team of investigative reporters last summer, an internal state audit showed that in the first three months of 1984, the hospital's five main psychiatric wards recorded an average of "zero to one" abuse complaint per ward to the advocate. (14)

In some institutions, patients/residents can rely on outside advocates who come into the facility to visit residents and observe the level of care being provided. Many states, such as New York and New Jersey, provide protection and advocacy services to monitor institutional care in state facilities. Families and interest groups have also organized to monitor institutional care and services.

However, it is often difficult for outside monitors to substantiate allegations of patient abuse. Access to client records is limited and credible witnesses are usually scarce.

Senate staff accompanied two state-paid investigators to one "multiple disabilities unit" of a state psychiatric hospital where two ward staff had charge of 12 young men dually diagnosed as mentally ill/mentally retarded. One patient complained he had been "beat up" by a staff member he named and said two other patients had witnessed the incident. The investigators attempted unsuccessfully to get coherent responses from the supposed witnesses. The staff member denied the incident. The investigators said they were unable to proceed further in the absence of any recent reported or observed injury.

Accompanying a lawyer-advocate to another state hospital, Senate staff observed a 16-year-old girl with a swollen index finger she said was caused by a staff member prying it back while attempting with other staff to place the girl in restraint. The girl further said she was beaten in restraints (while tied to a bed at four limbs). The lawyer later reported that the girl admitted lying about the swollen finger, but witnesses confirmed the beating in restraints. The lawyer was forced to conclude that the mixture of truth and untruth on the part of the complainant would make for a weak case and a low priority on heavy caseload.

While protection and advocacy services for the mentally retarded are expanding, such services are extremely limited for the mentally ill.

Last year, Congress amended the Developmental Disabilities Act to enhance the services and authority of state protection and advocacy agencies (P&A's) in institutions in two very specific ways. First, by no later than Oct. 1, 1986, P&A's must have access to records of institutionalized mentally retarded persons if (a) a complaint is received by the P&A and (b) the person does not have a legal guardian or the person is a guardian of the state. Second, the state must now provide copies of each annual survey of a certified facility for the mentally retarded along with the plan of corrections for deficiencies to the P&A. Both are to be received by the P&A within 30 days of completion.

Although the Developmental Disabilities Act does not specifically prohibit the state P&A's from providing services for the mentally ill, very few are served.

In a 40-state survey of services provided by P&A's, only seven percent of the total number of persons served were mentally ill.

One New Hampshire P&A attorney told Senate staff his agency's funding is inadequate to serve the mentally ill. "We can't generate business when we can't handle it," he said.

One P&A which does actively monitor and investigate state hospitals for the mentally ill is in New York. Recently the New York State Commission on Quality of Care for the Mentally Disabled conducted a review of living conditions in nine state psychiatric centers. The commission found that at the nine psychiatric hospitals there were "nine different thresholds of acceptable living conditions... What is startling is that these different thresholds do not, at most of the centers visited, reflect variations above a minimum standard, but in several instances affect the most rudimentary aspects of the obligation of a mental hospital to care for its patients--to provide them with a clean, safe and sanitary environment; clean, fitting and seasonably appropriate clothing; nutritious and tasteful food; proper personal hygiene; and an opportunity to engage in meaningful and constructive activities." (15)

In the past, federal grant dollars have been available to develop advocacy services for the mentally ill, like those provided in New York State.

Today, there are a few self-advocacy groups receiving funds from the National Institute of Mental Health but these are relatively small grants directed toward coordinating information and advocacy services among former patients of institutions for the mentally ill.

Senate staff believe protection and advocacy services for the institutionalized mentally disabled, especially the mentally ill, are desperately needed. There are few dollars specifically available for the mentally ill and many institutionalized mentally retarded persons have not been served by the P&A's. Based on data collected from 40 states, P&A's served approximately 30,000 persons in fiscal year 1982. However it is estimated that approximately 400,000 persons (both mentally ill and mentally retarded) reside in public institutions throughout the country. Considering the P&A's provide assistance on a range of issues (i.e. education, employment, transportation, vocational rehabilitation, medical services, housing, architectural barriers and guardianship) it is safe to assume that the vast majority of institutionalized persons do not receive services from the P&A's. Hopefully, the increased P&A appropriations approved by Congress for fiscal year 1985, as well as the new authority to serve institutionalized mentally retarded persons, will result in more institutionalized persons being served. However, until P&A services are further expanded, patients of state hospitals for the mentally ill will continue to be underserved.

Accreditation and Certification of State Hospitals for the Mentally Ill

Psychiatric facilities desiring to participate in Medicare and Medicaid must be certified by the Secretary of Health and Human Services. The first step in receiving certification is usually accreditation by the Joint Commission on Accreditation of Hospitals (JCAH), which satisfies federal requirements pertaining to physical environment, and health and safety. Currently, 348 of the 453 certified psychiatric hospitals are accredited by JCAH. In the 105 psychiatric hospitals which are not JCAH-accredited, the state agency conducts the general health and safety surveys, as well.

The second part of the process requires demonstrating that active treatment is being provided to residents of the facility. The survey to measure compliance with the active treatment standards is conducted, in 264 hospitals in 40 states, by consultants hired by the federal government with expertise in psychiatric care. In the remaining states, there are 189 certified hospitals, of which 76 are state-owned, where states used their own agencies to survey for active treatment.

The Joint Commission on Accreditation of Hospitals is a private, non-profit accrediting agency for hospitals, including psychiatric hospitals. It was chartered in 1951 as an outgrowth of the American College of Surgeons, which, from 1915-1951, conducted accreditation surveys of hospitals. JCAH activities are funded primarily from fees paid by facilities requesting accreditation, and from its five member organizations, which include the American College of Physicians; the American College of Surgeons; the American Hospital Association; the American Medical Association; and the American Dental Association. JCAH estimates that its fiscal year 1985 budget is approximately $22 million, 70 percent of which will be derived from survey fees. It receives no federal funding.

Accreditation Process

A psychiatric facility requesting accreditation is surveyed by a team of JCAH staff over a period of several days in order to assess compliance with over 1,600 standards. The length of the survey, and the number of surveyors is based primarily on the size of the facility. A psychiatrist is always present, along with up to six other surveyors. Surveys generally last between two and five days. The cost to the facility runs about $1,245 per day per surveyor. Surveys are conducted with approximately four weeks advance notice to the facility. Facilities requesting accreditation have the option of being surveyed under either of two JCAH manuals currently acceptable for psychiatric hospitals: the Consolidated Standards Manual for Child, Adolescent, and Adult Psychiatric, Alcoholism and Drug Abuse Facilities and Facilities Serving the Mentally Retarded/ Developmentally Disabled (CSM), or the Accreditation Manual for Hospitals (AMH). A comparison of selected portions of these two manuals is contained in a subsequent section.

Standards fall into seven categories: (1) patient management; (2) monitoring activities; (3) staff qualifications;

(4) quality assurance; (5) quality and appropriateness of care; (6) therapeutic environment; and (7) environmental safety. Compliance with standards is measured by the surveyors on a scale of 1 to 5, with a 1 representing substantial compliance, and a 5 representing noncompliance.

As part of the survey, JCAH reviews 10 percent of all patient records at random to assess whether treatment plans are in place, that charting is done regularly and correctly, and whether the treatment plans are being reviewed regularly and revised when appropriate. The surveyors also tour the facility, looking at the physical plant, treatment and living areas.

In addition to a review of patient records, surveyors hold two workshops during the survey on patient management and quality assurance. These workshops are attended by staff and administrators of the hospital and focus on areas in which surveyors have found weaknesses. Surveyors explain the applicable standards more fully to the staff and make suggestions regarding possible ways to improve compliance.

At the conclusion of the survey, an exit conference is held with administrators of the facility to discuss the surveyors' preliminary findings. At this time any serious deficiencies are brought to the attention of the administration and discussed. In cases where a situation is found that threatens the public or patient safety, JCAH policy calls for state or local officials to be notified in writing. However, JCAH has never issued such a notification.

After the survey has been completed, JCAH staff go through a complicated process of scoring the facility in each major category of standards, to come up with a composite score for the facility as a whole. If substantial compliance has been demonstrated in each of these categories, a decision to accredit the facility without deficiencies will be made. If there are some areas with deficiencies, a decision to accredit with contingencies may be made. Ultimately, if there are very serious deficiencies which have either occurred over a substantial period of time or are life-threatening, a non-accreditation decision may be made.

The ultimate sanction a facility may incur is loss of accreditation. JCAH reports that two psychiatric hospitals have been de-accreditated over the last year, and estimates that about two to three percent of psychiatric facilities lose their accreditation annually.

The Senate staff review revealed problems pertaining to the accreditation process that are of concern to patients and hospital personnel in view of the JCAH role in the certification process for psychiatric hospitals.

First, accreditation surveys by JCAH are predictable. When a facility requests initial accreditation, JCAH provides the hospital with the dates of the survey approximately four weeks in advance. Also, facilities know that the surveys will occur during normal working hours; evening or night visits do not take place. Additionally, facilities may contact JCAH prior to their survey to find out the names of the surveyors.

One hospital administrator in Texas said his facility took full advantage of the advance notification of JCAH surveys. "You can always find out who is coming and where they've been and prepare for him," the administrator said. After finding out where the particular surveyor had last worked, the administrator said, administrative staff from that facility were contacted to determine what items on the JCAH checklist seemed especially important to the particular reviewer. Confusion about certain standards, the administrator added, could be settled by telephoning JCAH headquarters in Chicago for an interpretation.

The predictability of JCAH surveys was of concern to the Southern Poverty Law Center in a brief filed on behalf of the plaintiffs in the Wyatt v. Ireland case. As noted in the brief:

> "...though regulators universally recognize that it is necessary for an inspection team to conduct unannounced

> visits if it is to obtain an accurate picture of how a facility functions (see Jarrell 18-19; Simmons Ex. 1 at 8, Attach. 1 at 4) J.C.A.H. notifies facilities, often months in advance, of when its survey team will be present. (Roberts 48). The commission recognizes that advance notification permits the facility to "dress up" its operations for the survey team and prevents the team from getting an accurate picture of its daily functioning. (See McAninch 256; Roberts 48)." (16)

Once accredited, hospitals must be re-surveyed every three years in order to assess continuing compliance with accreditation standards. Facilities are notified several months before their accreditation will expire, and a date is set for the survey during the 90 day period surrounding the survey anniversary date.

In cases where JCAH has accredited a psychiatric hospital contingent upon the facility's correcting specified deficiencies, the facility is notified three to four weeks in advance of the date on which a follow-up, or focused survey to measure progress towards correcting those deficiencies will occur. If, during a focused survey, the facility is still out of compliance with one or more standards, JCAH staff have several options. They may decide that a written progress report be filed by the facility, or that another focused survey be scheduled, or that the facility be de-accredited.

Approximately 50-60 percent of psychiatric hospitals are accredited with contingencies, and follow-up surveys are scheduled for three months, six months or a year after the initial survey, depending on the severity of the problem, and the amount of time JCAH feels is required to make corrections. A facility accredited with no contingencies will likely not see any JCAH surveyors during that three-year period, and approximately 40 percent of accredited psychiatric hospitals fall into this category.

When a focused survey occurs, facilities know in advance what the surveyors will be addressing: only those standards with which noncompliance was serious enough to warrant a "C" for contingency are examined during the focused survey. Lack of compliance with a specific standard for the first time is noted in the survey report. If that same deficiency is noted 3 years hence during the next survey, the survey report will likely contain a "+" next to the standard, indicating that the facility must be in compliance with that standard by the time of the next regular survey. If, during that survey, the problem has still not been corrected, a "C" may be placed next to that standard in the survey report, denoting that this problem must be corrected by the time of the next focused survey. JCAH indicates that facilities rarely, if ever, have only one deficiency; patterns of deficiencies in a particular category of standards are common.

As evidenced by the above explanation, a facility could be out of compliance with a standard for up to six years or longer before it becomes an issue which must be addressed before re-accreditation may be jeopardized. For example, a JCAH survey of one of the hospitals Senate staff visited indicated that the standard mandating that progress notes be made regularly had been violated on four previous surveys and was still not being met. Yet, a contingency was still not placed on the accreditation for noncompliance with this standard; a "+" was determined to be sufficient.

An additional criticism of the JCAH survey process is the limited extent to which sources outside of the hospital are contacted to obtain information about conditions inside the facility. It is true JCAH requires hospitals to post notice of an upcoming survey a month beforehand, to allow interested persons to apply to JCAH, in writing, for a public information interview during the survey. However, JCAH does not, on its own, initiate contact with state licensing officials or advocacy groups, who may well be able to provide information relevant to accreditation.

Although JCAH may initiate unannounced or unscheduled, 24 hour notice surveys of accredited hospitals, usually in response to complaints from individuals or newspaper articles, this is rarely done. In the last five years, only six such surveys have been initiated out of the approximately 530 accredited psychiatric hospitals. Before actually undertaking a survey, however, JCAH will usually share the complaints or articles with the facility and give them a chance to respond and rectify the situation. Only if JCAH has reason to believe the situation has not been corrected will it actually conduct a survey.

One former JCAH surveyor told Senate staff that such surprise-survey techniques would improve the Commission's ability to survey, but he said that, even with advance notice, hospitals are unable to make dramatic changes that alter the survey results.

A JCAH official, in a briefing with Senate staff, said of the routine advance-notice surveys, "We've agonized over this. How do you make sure they aren't trying to blow smoke at you?"

When asked about the JCAH accreditation process, staff of JCAH-approved facilities said a substantial amount of preparation is made for the Commission's reviews. Staff uniformly said efforts are made to "spruce up" hospitals, including extra cleaning, personalization of wards, new clothing for patients and especially, improvements in paperwork.

A therapist at a New Jersey facility told Senate staff she was instructed to assemble a selected group of patients on one ward JCAH was visiting to give the appearance of a scheduled class.

A direct-care staff worker in a Connecticut hospital said that, two to three weeks before the JCAH survey, "new stuff" began showing up on his ward, including plants, pictures on the walls, and "booties" (disposable footwear) for the patients. "Everyone all of a sudden got pajamas, toothbrushes, toothpaste; suddenly they were obsessed with cleanliness. After the reviewers leave, the stuff begins to evaporate with attrition," he said.

In addition to the amenities, there is the paperwork: "Anyone who has worked in an accredited public mental hospital is familiar with the panic that precedes visits from JCAH or other surveyors. During these panics staff concentrate on "treating the charts" and frequently neglect the treatment of patients." (17)

Direct-care staff take a cynical view of the JCAH process, noting that the ward improvements deteriorate after the commission surveyors depart as mentioned earlier. Apprised of these attitudes, facility administrators answer that the improvements are much the same as an individual would make in his own home in order to impress visitors.

An additional concern about the survey process is that facilities can hire consultants, both former and current JCAH employees or consultants, to survey the facility prior to the official JCAH survey. The current JCAH consultants who are in the business of doing these pre-surveys do provide JCAH with a list of facilities employing them within the last three years, so they will not be scheduled for an official JCAH survey of that hospital. The results of this consultation are used by the facility to determine where work needs to be done in order to have a successful survey by JCAH. While in itself this pre-survey consultation is not improper, it does suggest that facilities focus their efforts on achieving compliance just prior to their next JCAH survey, rather than maintaining compliance throughout the course of their three-year accreditation.

The JCAH proposal to require accreditation of all psychiatric hospitals under the Accreditation Manual for Hospitals (AMH) as of April 1, 1987 is troubling for a number of reasons, including the lack of standards in the AMH addressing patients rights. A review of the AMH revealed several problems in terms of the stringency of standards. For example, the set of standards delineating patients' rights are completely omitted, and the standards pertaining to special treatment procedures have serious weaknesses. The following is a comparison of the CSM standards pertaining to patients rights and special treatment procedures.

In the CSM, there are 6 major standards governing patients rights. These standards specify the facility's responsibility to (1) inform patients of their human, constitutional and civil rights and enforce those rights; (2) protect confidentiality of patients' records and patients' personal privacy; (3) inform patients and families regarding treatment and discharge plans; (4) obtain patients' informed consent for specific treatment modalities; and (5) allow patients to work for the facility only under specific conditions. These standards are totally absent from the AMH, and in lieu thereof is a statement in the front of the manual, of patients' rights and responsibilities. Although state laws may address these rights without commensurate standards, there is no formal measure of the extent to which these rights are protected.

Supporters of the shift to AMH standards have said that the more strictly worded regulations and procedures in sections of the CSM standards are in areas of the hospital function where "direct physician involvement has been relatively less intensive or more intermittent. This is particularly true for services that involve significant risk for the patient."

In the CSM, such "highly prescriptive and detailed" procedures include those for seclusion and restraint of patients. The standards "specified details of charting appropriate indications, and the administrative review of these procedures. By contrast, the AMH mentions seclusion and restraint under the standard describing the bylaws and accountability of the medical staff. The entire reference to restraint and seclusion encompasses one paragraph...One implication of these shifts from the consolidated standards to the AMH for hospital-based psychiatric care is that psychiatry will have the same responsibility as other medical specialties to monitor its activities. It seems likely, therefore, that psychiatrists will participate increasingly, along with other physicians, in establishing and implementing quality assurance programs." (18)

Restraint and seclusion standards in the CSM mandate that the facility must (1) establish a written policy governing the use of restraint and seclusion (r/s); (2) justify clinically the need for r/s, and not allow use of r/s for punishment or convenience of staff; (3) have a physician's authorization for the use of r/s, which cannot exceed 24 hours; (4) see that staff are trained in the use of r/s; (5) not allow r/s to be used in a manner causing undue pain or discomfort; and (6) attend to the patient in r/s every 15 minutes, and allow him to bathe, use the toilet and receive meals. By comparison, the AMH standards are considerably weaker. The only requirements are that a physician must write a "time-limited" order for r/s within 12 hours after its initial use, and that the patients be attended to every 15 minutes as discussed in (6) above. Notably absent are restrictions limiting restraint or seclusion to 24 hours, with staff being able to place a patient in r/s and not receive authorization for it until well after the fact, and the elimination of the requirement that staff be trained in the use of r/s. The most serious omission here are the standards stating that r/s is not to be used as punishment or for the convenience of staff and that r/s are not to cause undue discomfort or pain. Again, often because no formal method of evaluating the use of restraint and seclusion exists outside of the JCAH standards, any weakening of these standards could jeopardize protection of patients' safety and health.

These categories of standards were chosen for comparative purposes because they illustrate how fundamental areas of patient care are -- and are not -- addressed by a private organization to which the federal government has transferred considerable authority to determine whether a psychiatric hospital may become eligible for federal funds.

JCAH admits that the controversy surrounding the AMH may result in alterations to the manual before it completely replaces the CSM in 1987, perhaps including a section on patients' rights. The Health Care Financing Administration accepts accreditation of psychiatric hospitals under either manual, although most hospitals have chosen accreditation under the CSM.

Several hospital administrative staff interviewed by Senate staff were critical of the scheduled shift from the CSM to the AMH manual by JCAH. The most common complaint centered on the medical model embodied in the AMH standards, which gives the preeminent supervisory role in treating patients to the psychiatrists. It was felt that the CSM encourages a more multi-disciplinary approach to treatment that requires less costly outlays for medical staff, a significant concern for state run facilities that largely must rely on state-appropriated funds.

Several psychologists at different hospitals told Senate staff that they and the nursing staff have the actual primary responsibility for treating psychiatric patients, beyond the routine prescription and review of medications that is the psychiatrists' job. Underlying much of the criticism was a feeling that JCAH had "buckled" to pressure from medical professionals' organizations in requiring the shift. There was also strong sentiment questioning the ability of institutional psychiatrists, often foreign medical graduates, to assume broader treatment responsibilities.

A JCAH official privately acknowledged that the quality of the medical staff in public facilities is a problem in terms of their ability to provide active psychiatric treatment. However, this official also contends that the increased emphasis on competency of the staff in the AMH will force the public psychiatric hospitals to recruit and maintain a better qualified cadre of physicians, including psychiatrists.

As noted previously, JCAH has delayed requiring the shift from CSM to AMH from its original deadline. An administrator at a Colorado hospital told Senate staff the delay is evidence that the AMH shift for psychiatric facilities "is going to die (because) it wasn't conceived logically or rationally". Many public hospitals are resisting the change to the AMH, according to JCAH, and are not making a good faith effort to improve the quality of their medical staff. Recognizing the difficulty some state hospitals may have in making the transition to the AMH, JCAH indicates it will allow them additional time to come into compliance with the new standards.

Finally, JCAH standards focus heavily on compliance with paperwork requirements. As noted in a recent article in Hospital and Community Psychiatry, "Documentation cannot be ignored, nor should it be. But there ought to be more reliance on surveyor's judgment in lieu of excessive documentation." (19) For example, compliance with the standards pertaining to treatment plans is based on whether written documentation exists that demonstrates that such a plan has been developed, that services are being provided to carry out the objectives of the plan, and notations made regarding a patient's progress toward meeting those objectives. However, those standards do not require surveyors to visit areas of the facility where therapeutic procedures are carried out to see if, in fact, the treatment specified in the plan is going on. JCAH staff indicate that during their tour of the facility, surveyors select a few active charts and sit in on treatment team meetings and therapy sessions involving those patients. However, this is not a formal procedure mandated by JCAH, but an informal check to see that treatment is in fact going on.

This reliance on written documentation can lead to a situation where psychiatric facilities, in preparation for a JCAH survey, may do "catch-up" work to bring patients' records and treatment plans up to date in order to satisfy paperwork requirements.

During the Senate staff review, such an allegation was made against one visited facility. A staff member reported that prior to a JCAH survey, documentation would be added to patients' records to indicate that certain treatment procedures, such as psychotherapy, were taking place, when in fact they were not. This staff person also alleged that charts which had not been kept up to date or were not "presentable" would be hidden in order to avoid inspection by the surveyors. Senate staff heard from sources familiar with this facility that very little, if anything, in the way of treatment is provided to patients, aside from medication.

A former employee of one hospital told Senate staff that JCAH surveyors reminded the staff that patients' records should never be altered. This would indicate that the surveyors noticed that changes had been made in some records, but decided not to confront the issue directly. In this particular case, JCAH made a decision to re-accredit the hospital. Contingencies were placed on that accreditation, but were not related to treatment plan or patient record requirements.

There is a widespread impression that JCAH reviews only the bureaucratic functions of a hospital. A Texas administrator said that, because of JCAH, "We do a much better job of writing than we ever did and to a lesser degree, a better job of programming."

A direct-care worker in the same facility said, "I don't think they sample what's important. They want us to do well. (Their review) has no connection to patient care."

A programming specialist (teacher) at a New Jersey hospital told Senate staff: "what JCAH looks at mostly is the paperwork and the charts. From my experience, they examine the program very little. They really are much more interested in seeing what's on paper, seeing what programs are on paper and treatment plans completed and up to standard, progress notes completed..."

The concern that JCAH surveys focus too heavily on paperwork is shared by the Southern Poverty Law Center in the Wyatt v. Ireland brief mentioned earlier. The brief states:

> "...in practice, the survey team must rely primarily on what is contained in hospital records and on what they are told by hospital administrators...Because the survey process does not assure that the information obtained from these sources will accurately portray the internal functioning of the facility, (see Jarrell 32; Warner 64-65) the conclusions of the survey team concerning the facility and whether it promotes the provision of quality care cannot be relied upon...As a result of the peculiar focus of the Commission's survey process, the Commission's investigations are not designed to assess whether the treatment planned and provided by a facility is adequate or meets patients needs, (see Simmons 12,63; Warner 29,55) by far

the greatest flaw in the Commission's survey process." (20)

This sentiment is echoed by direct-care staff who further report that JCAH surveys do not examine what the staff feels is the most important task of the hospital: care of patients. Many staff said they welcome independent reviews of patient care, noting the occasional administrative shakeups, reviews by state legislative groups, and press investigations resulting in increased attention on, and improvements to patient care.

In sum, reliance on accreditation by the JCAH as a determinant in Medicare/Medicaid eligibility may not be appropriate because the standards set forth in federal statutes cannot be assumed to be met simply because a psychiatric facility is accredited.

Certification Process for Psychiatric Hospitals

An additional opportunity for the federal government to monitor conditions in psychiatric hospitals exists when those facilities desire to participate in the Medicare and Medicaid programs. Psychiatric facilities must be certified by the Secretary of Health and Human Services in order to receive federal funds through the Medicare and Medicaid programs, established by Titles XVIII and XIX of the Social Security Act, respectively. This certification is granted to facilities that first demonstrate they meet both health and safety standards established for all general hospitals, as well as two special conditions applicable specifically to psychiatric hospitals.

Coverage

Medicare covers individuals aged 65 and over for a lifetime benefit of up to 190 days for inpatient psychiatric care. Individuals under the age of 65 may be also covered if they have been receiving Social Security benefits for 2 years as a result of disability, with the same 190-day lifetime benefit restriction.

Medicaid coverage of inpatient psychiatric care is an optional benefit which is currently offered by 40 states for individuals age 65 or older, and in 33 states for those under 22. Individual eligibility for Medicaid inpatient psychiatric care extends only to those individuals under the age of 22 and 65 years or older. In other words, the adult population from 22 to 65 are not covered for these services, even if they would be eligible for Medicaid if not hospitalized.

The Health Care Financing Administration (HCFA) estimates that in fiscal year 1983, federal Medicaid expenditures totaled approximately $615 million and Medicare expenditures were roughly $200 million for inpatient psychiatric care rendered in psychiatric facilities. These amounts exclude reimbursement for psychiatric care provided in general hospitals, for which data is not available. HHS estimates that reimbursement to general hospitals for inpatient psychiatric care may increase total Medicare and Medicaid expenditures by several hundred million dollars.

Certification

As mentioned above, the first step in becoming a certified psychiatric hospital requires that a hospital meet federal health and safety standards applicable to all general hospitals. Until July, 1984, the Social Security Act mandated that this requirement had to be satisfied through accreditation by the JCAH. However, Medicare regulations allow part of a hospital to participate in Medicare in cases where the entire hospital is not JCAH-accredited. Through this provision, the state, usually the health department, surveys the hospital. If the "distinct part" of the hospital meets the federal requirements for psychiatric hospitals, the state agency would recommend certification to the Health Care Financing Administration (HCFA) regional office. The regional office, assuming there were no other problems, would then certify the facility as a "distinct part". The philosophy behind this provision is to allow a hospital which could not meet JCAH standards in their entirety to focus its resources, particularly staff, in a smaller area, thus, bringing this area (perhaps a wing, or even one or more buildings of a multi-building facility) into compliance with federal standards. Therefore, non JCAH-accredited psychiatric hospitals can be eligible for federal money. Of the 430 psychiatric hospitals currently participating in Medicare and/or Medicaid, 345 are accredited by JCAH.

The Deficit Reduction Act of 1984 (DEFRA), included a provision repealing the Social Security Act requirement that psychiatric hospitals must be accredited by JCAH in order to participate in Medicare and Medicaid. JCAH had sought this amendment for years because of its belief that legislatively mandating accreditation for the purposes of Medicare and Medicaid eligibility largely removes the voluntary nature of the accreditation process. JCAH staff stated their view that psychiatric hospitals do a better job of meeting standards when they do so of their own volition.

This change in the law does, however, allow a non-accredited psychiatric facility desiring to participate in Medicare and Medicaid to apply to the state agency for a survey to determine compliance with federal standards. Prior to DEFRA, state agencies could only conduct surveys of "distinct parts" of non-accredited facilities. In addition, DEFRA gave the Secretary of Health and Human Services the authority to rely on other, unspecified accrediting agencies to determine compliance with

Medicare requirements. Nevertheless, HCFA indicates it has no plans to recommend using any other agencies for this purpose.

Special Conditions Pertaining to Active Treatment

After demonstrating compliance with federal health and safety standards, either by virtue of accreditation by JCAH or a successful state agency survey, psychiatric hospitals must also show that active treatment is being provided to patients of the hospital. The provision of active treatment is mandated by the Social Security Act. However, nowhere in the Social Security Act or in the conditions of participation set forth in the regulations is the term "active treatment" actually defined. Even though it is not defined, it is to be measured by compliance with two special conditions pertaining to the adequacy of medical records and qualified staff, which are discussed below.

The first special condition states that the medical records maintained by a psychiatric hospital must be sufficient to determine "the degree and intensity of the treatment provided" to residents of the facility. (42 CFR, Chapter IV, Subchapter B, Sec. 405.1037). The 12 components of this requirement all necessitate that an examination of patients' medical records be made for documentation of psychiatric history and diagnosis, treatment plans and procedures, and progress notes.

The other special condition mandates that sufficient numbers of qualified staff are employed by the facility to implement plans of active treatment for residents of the facility. In some cases, the types of qualifications for certain staff are specified, but not uniformly. In determining the numbers of staff, "adequate" and "sufficient" are the guidelines to be followed. No ratios of staff to patients are set forth, leaving the surveying agency to decide if enough staff are present to carry out treatment plans.

The regulations do not specify what "active treatment" consists of, but state that the physician must certify that "services were required for either: (1) treatment which could reasonably be expected to improve the patient's conditions; or (2) diagnostic study". (42 CFR, Chapter IV, Subpart P, Sec. 405.1629 (a)). Additionally, the training manual for NIMH consultants states that the objectives are:

> "1. To assist the patient to attain or restore to optimal psychological, psychological, physical and/or social function of which he/she is capable.
>
> 2. To improve the patients' condition to the extent that eventually such services requiring hospitalization will no longer be necessary." (21)

Neither of these objectives indicate what treatment is to consist of nor how to achieve it.

Under Medicare the states are responsible for surveying psychiatric facilities to assess whether they comply with all the applicable conditions of participation. However, in the case of the two special conditions, states experienced substantial difficulty in recruiting and maintaining the cadre of qualified psychiatrists, psychiatric nurses and psychiatric social workers needed to assess compliance. Additionally, there was a concern that a conflict of interest might arise when a state agency was responsible for recommending certification of its own psychiatric facilities.

As a result, in 1969, an agreement was entered into between the Health Care Financing Administration (HCFA), which administers the Medicare and Medicaid programs, and the National Institute of Mental Health (NIMH) whereby NIMH would recruit such professionals as consultants to be available to states upon request to conduct these surveys. From 1969 until January 1, 1985, states were able to request NIMH assistance in conducting these surveys. NIMH data indicate 40 states used NIMH consultants for this purpose, while six conducted their own surveys, and four have no participating psychiatric hospitals. However, the six states with certified psychiatric hospitals that do not use the NIMH consultants contain nearly half the nation's mentally ill population residing in state psychiatric hospitals. These states are New York, New Jersey, Georgia, Minnesota, Illinois, and Wisconsin. HCFA indicates that 253 of the approximately 432 certified psychiatric hospitals were surveyed by NIMH consultants in FY 1984.

The 80-90 consultants hired by NIMH to conduct these surveys have been professionals in the fields of psychiatry, psychiatric nursing, psychology, social work, pharmacy, and activity therapy. All were currently working in their fields, and did surveys for NIMH several days a month.

But, beginning in January 1985, this interagency agreement was terminated. The reason cited by HCFA and NIMH for the termination was that the four full-time personnel positions needed to administer the program at NIMH were no longer able to be absorbed within the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) personnel ceiling. Over the last few years, ADAMHA has undergone substantial staffing reductions, with NIMH suffering the preponderance of reductions. Under an HHS rule, heretofore unenforced in this case, an agency requesting services from another agency must provide the personnel to carry out the requested service, and HCFA was unable to provide NIMH with the four personnel positions, again because of staff reductions. The first quarter of fiscal year 1985 was a transition period during which NIMH continued to run the program, after notifying HCFA that it would not be able to administer the program after Jan.1, 1985.

HCFA has now taken over the administration of the surveys for the two special conditions. HCFA indicates that it will continue to use the same consultants employed by NIMH, but that it will contract out for the administrative management of the survey program. HCFA has issued a request for contract (RFC) for this purpose, stipulating that NIMH consultants continue to be used.

Several of the NIMH consultants have expressed concern that NIMH will no longer be administering the program. Because of the credibility of NIMH in the mental health community, and the responsiveness of NIMH staff in providing technical assistance to surveyors, some consultants are fearful that the lack of HCFA staff expertise in this area will jeopardize the integrity of the survey process. The concern was also raised that an agency, such as a management firm, would seek to minimize costs, maximize profits, and thus encourage less rigorous surveys. Nonetheless, HCFA asserts that it has added the necessary expertise to its staff with two psychiatric nurses, and will closely monitor whatever contract is implemented to ensure the quality of the surveys. HCFA further indicates that the former NIMH consultants have unanimously agreed to continue to conduct the surveys for HCFA. Neither HCFA nor NIMH are pleased that the interagency agreement was terminated.

Several issues are of concern in the certification and monitoring processes for psychiatric hospitals participating in the Medicare and Medicaid programs. One of the underlying problems is the vagueness of the Social Security Act provisions determining the criteria for participation by psychiatric hospitals. The legislation, while mandating that "active treatment" be provided, is silent as to what constitutes "active treatment". The same is true of the regulations stating the conditions of participation for psychiatric hospitals. With no legislative or regulatory statement of the methods by which to accomplish active treatment or the goals of such treatment, assessments of whether sufficient qualified staff and adequate medical records exist to carry out active treatment become a subjective decision.

Second, while statutory authority exists for HCFA, through appropriate state agencies, to conduct surveys of psychiatric hospitals to ascertain whether they are meeting statutory conditions of participation, this authority is underutilized. The Social Security Act gives the Secretary of Health and Human Services the authority to enter into agreements with states whereby appropriate state agencies may conduct validation surveys of JCAH-accredited facilities. Hospitals are chosen for these validation surveys either on a selective-sample basis, or on the basis "of substantial allegations of the existence of a significant deficiency or deficiencies which would, if found to be present, adversely affect health and safety of patients." (Social Security Act, Section 1864 (c)). The regulations implementing this section state that a "substantial allegation means a complaint which reflects on the health and safety of patients and raises doubts as to a hospital's compliance with the conditions of participation." (CFR 42, Chapter IV, Section 405, Subpart S, Section 405.1901) Therefore, HCFA may initiate surveys, for example, in response to complaints of abuse, which clearly affect the patients' health and safety.

However, HCFA has not aggressively used this tool to ascertain compliance, and estimates that, at best, only five percent of psychiatric facilities receive validation surveys on an annual basis. In fiscal year 1983, HCFA stated that only 12 validation surveys were conducted of the 348 JCAH-accredited hospitals participating in Medicare and Medicaid. HCFA may also send its own staff to survey a facility, usually based on complaints regarding quality of care. While information provided by facilities visited during the course of Senate staff's review indicate that every one has taken disciplinary action against staff for confirmed cases of abuse of patients, HCFA was unable to provide Senate staff with the number of unannounced visits it conducted over the last year in response to complaints.

A third area of concern pertains to the time frames established for correction of deficiencies found during a state certification or validation survey. The regulations provide that facilities found to have deficiencies must submit a plan for correcting those deficiencies "within a reasonable amount of time acceptable to the Secretary." (42 CFR, Chapter IV, Subpart S, Section 405.1907) The regulations further provide that the state survey agencies must monitor facilities to ensure that corrections are, in fact, made during that period of time. However, this monitoring may or may not include on-site visits to measure progress; written reports frequently suffice.

These time frames are to be determined after taking into account "the nature of the deficiency, and the state survey agency's judgment as to the capabilities of the facility to provide adequate and safe care". (42 CFR, Chapter IV, Subpart S, Section 405.1907 (b)). Although 60 days is the regulatory guideline for correcting deficiencies, the state agency may recommend additional time if it is not "reasonable to expect compliance within 60 days" (42 CFR, Chapter IV, Subpart S, Section 405.1907 (b)).

With no federally-mandated time frames for correction, a facility which is able to demonstrate progress toward correcting deficiencies is rarely, if ever, decertified, even if agreed-upon deadlines are not met. Certified psychiatric facilities can be terminated from Medicare and/or Medicaid in the case of "immediate jeopardy", which HCFA indicates has never been done.

Additionally, there is a potential for a conflict of interest when it is the states themselves, through their survey agencies, which must certify to the federal government that facilities within their borders meet the Medicare and Medicaid requirements. In the case of a state hospital, the financial consequences of decertification are great: whatever federal funds are lost as a result of termination from Medicare and Medicaid must be made up, to the extent possible, with state funds. Therefore, there are substantial disincentives for a state to decertify a state-run facility, and all the more reason to give a hospital with deficiencies as much time as possible to come into compliance. The following situation, which came to the attention of Senate staff during the course of the investigation, dramatizes this potential conflict of interest.

During the 1984 Medicaid state survey of a state-run psychiatric hospital, the survey team reported that "nursing services have deteriorated to such a degree that care does not meet minimally acceptable standards." (emphasis not added) This language was a replacement by a state official of a description by the survey team, which had determined and written that nursing services were "negligent". The language was virtually identical to language contained in the team's 1983 report, which concluded with the statement that "...significant improvement in the areas of nursing and social services should be undertaken immediately...".

Yet, in 1984, the level of nursing care was still found to be extremely poor. The hospital was told to submit a plan of correction addressing these and other deficiencies within 30 days. The nurse on the survey team expressed frustration that no attempts to investigate or de-certify the facility had been undertaken, even after two years of documented serious deficiencies. Even though facilities can be terminated from Medicare and Medicaid participation if deficiencies jeopardize the health and safety of patients, a decision was made at the state level that the quality of nursing care had not, in fact, deteriorated to that level. Even though the HCFA regional office receives copies of these survey reports, no survey has been initiated as a result of these negative reports.

Fifth, no minimally acceptable levels of care are specifically mandated under the Social Security Act or the implementing regulations. The regulations do permit exclusion or termination from the Medicare and Medicaid programs or a disallowance of federal Medicaid payments previously made when the services of a participating psychiatric hospital are "of a quality that does not meet professionally recognized standards of health care". (42 CFR, Chapter IV, Subpart B, Section 420.101 (2)). The determination that a facility is providing substandard care is made on the basis of documentation provided by several sources, including state licensing or certification authorities, peer review organizations, professional societies, and "other sources deemed appropriate by HCFA". (42 CFR, Chapter IV, Subpart B, Section 420.101(b)).

Again, the decision to terminate a facility from participation becomes a subjective one, due to the lack of mandated minimal levels of compliance. Additionally, the survey reports of JCAH are not regularly provided to the Secretary of Health and Human Services. In fact, the Social Security Act protects the confidentiality of the surveys, and requires only that the survey reports be released to the Secretary, or the state agency as her designee when requested. Therefore, the situation often arises that HHS may not even be aware of deficiencies in JCAH-accredited facilities unless it receives a complaint that subsequently prompts a survey.

Finally, the question arises as to how diligently the states, to which the federal government has entrusted much of its power to conduct certification and monitoring, actually carry out these responsiblities. The state survey agencies play extremely powerful roles in determining whether psychiatric hospitals may participate in Medicare and Medicaid. While these agencies have the leverage of severe sanctions, including decertification, these tools are not aggressively used. Hospitals need only demonstrate that they are trying to come into compliance to be granted frequent extensions of deadlines. Unless the federal government assumes a more active role in assuring that health and safety standards are met, and that the intent of the legislative mandate for active treatment is fully implemented, the quality of life for patients in many psychiatric hospitals will continue to be, at best, substandard.

Certification of Institutions for the Mentally Retarded

Medicaid is the major federal source of funds for residential and related services for mentally retarded and other developmentally disabled persons.

Under the federal Medicaid law (Section 1905(c) of the Social Security Act), an intermediate care facility is an institution which: (1) is licensed under state law to provide, on a regular basis, health-related care and services to individuals who do not require the degree of care and treatment which a hospital or skilled nursing facility is designed to provide, but who, because of their mental or physical condition require care and services (above the level of room and board) which can be made available to them only through institutional facilities; (2) meets standards prescribed by the Secretary of Health and Human Services as he or she finds appropriate for the proper provision of this care; (3) meets standards of safety and sanitation which are established by the Secretary in regulation in addition to those applicable to nursing homes under state law; and (4) meets requirements for protection of patients' personal funds.

In 1971 the Medicaid statute was amended to allow for federal reimbursement to institutions serving mentally retarded and other developmentally disabled persons. The statute specifies (section 1905(d)) that intermediate care facility services may include services in a public institution (or distinct part thereof) for the mentally retarded or persons with related conditions if among other things: (1) the primary purpose of the institution (or distinct part thereof) is to provide health or rehabilitative services for mentally retarded individuals and the institution meets such standards as may be prescribed by the Secretary; and (2) the mentally retarded individual is receiving active treatment. These facilities are called intermediate care facilities for the mentally retarded and persons with related conditions (ICFs/MR).

The regulations at 42 C.F.R. 435.1009 define "persons with related conditions" to mean individuals who have epilepsy, cerebral palsy or other developmental disabilities as defined under the Developmental Disabilities Services and Facilities Construction Act, P.L. 91-517, as amended.

Since Medicaid is primarily a state program, the responsibility for annually surveying and certifying ICFs/MR lies with a state designated agency. The state agency may not enter into a provider agreement with a facility unless it has certified that specific standards are met. The certification process involves an on-site visit by the state certifying agency, responsible for assessing the facilities' compliance with 693 survey items representing 116 standards. If a standard is not met it is considered a deficiency and the facility must submit a plan of correction to the state. The state is responsible for monitoring the plan of correction for each deficiency. If the corrections are not made the state can continue to certify the facility if it is determined that a good faith effort was made towards meeting the plan.

States are authorized to terminate a facility from the

Medicaid program if the deficiencies jeopardize the resident's health and safety or seriously limit the facility's ability to give adequate care.

However, from 1981 to May 1984, no state terminated the Medicaid eligibility of an ICF/MR facility with 15 beds or more.

The authority of the state to certify its facilities for federal reimbursement creates a possible conflict of interest since the state must determine whether or not its facilities are eligible for those funds. If it determines that they are not eligible, then in all probability the state itself would have to make up the loss of federal funds with state funds.

In a brief filed on behalf of the plaintiff in Wyatt v. Ireland, the Southern Poverty Law Center addresses the issue of state agencies surveying state institutions and quotes two experts on certification/accreditation.

"As Dr. Steven Taylor, a Syracuse University professor who has extensively studied the Medicaid survey process, notes:

> 'I consider that an inherent conflict of interest (exists) with one state agency monitoring another state agency given the large amount of Medicaid dollars at stake and given the fact that in many states these Medicaid dollars are important to services. I think ...there may be a built in tendency for the monitoring not to be as rigorous as it might be were a totally independent body involved in the monitoring. That's an inherent weakness in the surveying process.'

"Kenneth Crosby, the Director of the Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled persons (ACMRDD), a national accreditation agency for facilities for the mentally retarded, has been told by state ICF/MR surveyors that deficiencies identified by on-site surveys are sometimes removed at an administrative level following submission of their reports. In Dr. Crosby's own words,

> '...It was made very clear that certain state survey agencies at least did not want their surveyors to make accurate and reliable assessments of compliance with the Medicaid Standards, because had they done so it might have resulted in loss of federal funds by state operated facilities.'

(Crosby 19-20; see Hubbard 21; Cook; Klebanoff 42-43)." (22)

Federal Monitors

A check on this potential conflict of interest is the Federal "look-behind" authority. In 1980, P.L. 96-499 authorized the Secretary of Health and Human Services (HHS) to conduct surveys to make an independent determination of a facility's compliance with requirements. The Secretary of Health and Human Services is authorized to terminate a facility's participation in Medicaid if there is immediate jeopardy to the health and safety of the residents or if the deficiencies seriously limit the facility's capacity to give adequate care.

Senate staff, however, has found that the Department of

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Health and Human Services "look behind" activity has been limited and does not ensure timely corrections of policy or practice when deficiencies are identified. In 1984, look behind surveys were conducted in only 5 percent of the 2,200 ICFs/MR. To enhance the ability of HHS to send more surveyors into ICFs/MR to review state certification findings and to increase the presence of federal monitors, Congress, at the initiative of Senator Weicker, included the funds for 45 new look behind surveyors in the Fiscal Year 1985 HHS appropriations bill (P.L. 98-619). The Health Care Financing Administration estimates that with the additional 45 surveyors it could conduct look behind surveys annually for 100 percent of facilities with 300 or more beds; for 40 percent of facilities with 16-299 beds and for 20 percent of facilities with 15 beds or less. As of Feb. 14, 1985, HHS indicated that 36 of these positions had been filled.

In a July 31, 1984 hearing held by the Senate Subcommittee on the Handicapped and the Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies, Secretary Heckler presented the results of 17 look behind surveys HHS had recently conducted. Secretary Heckler stated:

> "All of the 17 facilities inspected were substandard. Nine had major health and safety deficiencies... In all cases where substandard conditions were noted during the recent Federal inspections, State medicaid directors have been given 30 days to respond with a firm, detailed plan for correcting these deficiencies within 180 days. Failure to deliver an acceptable plan or inadequate

> implementation of that plan will result in termination of the facilities from the Medicaid Program."

Aug. 31, 1984 marked the deadline for receipt of these plans. In a Dec. 19, 1984 letter to Senator Weicker, Secretary Heckler stated that HHS had approved plans for seven of the nine facilities that had major deficiencies and the HCFA Regional Offices had approved five plans of correction. Five plans were outstanding at that time. Four months after the stated deadline, HHS had still not approved five plans of correction for institutions in which federal monitors had noted substandard conditions. In a March 4, 1985 letter, six months after the deadline, Secretary Heckler stated that plans of correction had been approved for 16 of 17 facilities.

Even when an institution submits a plan of correction there is no guarantee that actual corrections will be made. Repeatedly, an institution can re-submit plans of correction if deadlines are missed or plans do not initially receive HHS approval.

In the 1982 brief filed on behalf of the plaintiffs in Wyatt v. Ireland, the Southern Poverty Law Center included an analysis done by Dr. Steven Taylor of the Medicaid records at Mansfield Training School in Connecticut from 1978-1981. This analysis provides a graphic example of how long deficiencies may continue before being corrected.

> "In 1978, the average number of deficiencies found at the seven different units at Mansfield was 69. By 1981,

there were an average of 151. The facility's compliance with the Medicaid Standards actually decreased over time! (Taylor 32).

"As already noted, where deficiencies exist, Medicaid requires the preparation of plans of correction, which are designed to bring facilities into compliance with the Medicaid standards. Yet at Mansfield, the percentage of deficiencies corrected actually decreased over time from 55 percent in 1978 to 16 percent in 1981, 'indicating that the facility was less able in 1981 to correct deficiencies than it was in earlier years.' (Taylor 33). Further, the deficiencies noted for correction often appear year after year in survey reports even though they have been repeated as corrected in the course of the previous survey year. (Taylor 25-29)... Dr. Taylor's report found a telling example:

> 'In one deficiency report we reviewed, we found that the deficiency stated that residents were lying in their own feces and urine during the day. The plan of correction was simply to state that our nursing policy will be revised to state that residents shall no longer lay in feces and urine.'

Plainly, the Medicaid process tends to minimize the importance of planning and permits acceptance of the most meager types of statements as so called "plans of correction". Equally plainly, serious deficiencies cannot be rectified without detailed planning."

The brief continues to explain:

> "The deficiencies also go uncorrected because, even where deficiencies are found, the criteria for deciding not to grant or to continue decertification are so ambiguous as to give ready play to the impulse to certify that affects both state and federal levels of the Medicaid system. The initial certification decision depends on the state survey agency's acceptance of the agency's plan of correction, but, the determination of whether or not a plan of correction is acceptable is left simply to 'professional judgment'. (Green 166-68). Should the federal government conclude that a state certified institution in fact does not satisfy the requirements for participation in the Medicaid program, it too retains discretion not to proceed to terminate the institution, and it too makes its decision without guidelines that provide criteria for deciding that particular deficiencies require termination while others do not. (Boone 148-49)." (23)

HHS can withhold payments to facilities for a period of time for certain deficiencies. Although HHS has withheld payments, it has only terminated one facility from the Medicaid program. Bellefontaine Habilitation Center in St. Louis, Mo. was terminated from the program in April 1984 for deficiencies of immediate jeopardy to the health and safety of the residents. This facility was later recertified when corrections were made.

Like the HHS look behind survey, state surveys focus more on written policies and plans than actual practice and treatment.

Survey standards outline requirements for administrative policies and procedures, personnel policies, resident living standards, staffing, safety, sanitation and others. One critical component of these standards is the concept of active treatment. The current regulations address active treatment in the following manner:

> Active treatment in institutions for the mentally retarded requires the following:
>
> (a) The individual's regular participation, in accordance with an individual plan of care, in professionally developed and supervised activities, experiences, or therapies.
>
> (b) An individual written plan of care that sets forth measurable goals or objectives stated in terms of desirable behavior and that prescribes an integrated program of activities, experiences or therapies necessary for the individual to reach those goals or objectives. The overall purpose of the plan is to help the individual function at the greatest physical, intellectual, social, or vocational level he can presently or potentially achieve.

The survey instrument contains measures of active treatment, such as the requirement that a training and habilitation plan be developed for each resident and staffing ratios for direct care workers.

However, the majority of certified institutions surveyed by the Department of Health and Human Services prior to the July 31, 1984 hearing, discussed previously, were cited for their failure to provide active treatment. For example, a February 13-24, 1984 look-behind survey at Mansfield Training School in Connecticut found the active treatment rate to be 44 percent. This was considered to be "unacceptably low." A July 25, July 28, and Aug. 10, 1984 survey of Mansfield Training School noted the following:

> "On day one of the survey, three residents were observed in the residence throughout the morning with no active staff/client interaction of any kind. One resident was observed repeatedly engaging in potentially self-dangerous behavior for a two hour period without staff intervention. The one staff member on duty in the residence was engaged in clerical and housekeeping duties."

Other recent surveys stated:

> "Many clients were observed in meaningless tasks and inactivity in living units." (From a February, 1984 survey of Bellefontaine Habilitation Center, St. Louis, Missouri.)

> "Quality, quantity and intensity of treatment programming provided to clients has been reduced to an unacceptable

degree." (From August, 1984 survey of Letchworth Village Developmental Center, Thiells, N.Y.)

"On one of the units, a client was lying on the floor directly adjacent to a radiator. When questioned the staff member responded that the client usually did this because he liked the warmth. This indicated evidence to us for client reprogramming and staff reeducation training." (From an August, 1984 survey of J. N. Adam Developmental Center, N.Y.)

"The seven clients were either sitting listlessly in chairs or pacing aimlessly around the room." (From an April, 1984 survey of Newark Developmental Center, Newark, N.Y.)

"Of 47 records reviewed, only 9 were receiving active treatment... Because of the lack of program plans for many residents, the residents were observed to be spending several hours in their cottage placements in unstructured activities." (From a February, 1984 survey of Pauls Valley State School, Pauls Valley, Oklahoma.)

All of the ICF/MR standards are 10 years old and in need of updating. HCFA has held a series of meetings and received input from over 21 groups and agencies concerned with revising the regulations. In particular, Secretary Heckler told Senator Weicker in April 1984 that much effort has gone into refining the active treatment standards so they will be enforceable and result in appropriate treatment of residents. The issuance of new regulations, the Secretary said, would be at the top of her agenda. As of the spring of 1985, however, Secretary Heckler was still unable to predict when a notice of proposed rule making would be issued.

It is interesting to note that, despite the attention being focused on the need to improve active treatment, the Office of the Inspector General (OIG) of HHS has recently begun a series of audits intended to recover funds spent in ICFs/MR for training. The OIG has completed audits in seven states and recommended withholding a total of approximately $34 million in federal Medicaid funds. According to the OIG, the federal government could save about $585 million over the next five years if the recovery of funds continues.

The Inspector General contends that Medicaid coverage for education and vocational training is precluded, and that only habilitation services are eligible for reimbursement. However, the ICF/MR regulations require that services be provided which "help the individual function at the greatest physical, intellectual, social or vocational level he can presently or potentially achieve."

In Iowa, HCFA has been reimbursing the state for rehabilitation services which HHS now classifies as educational. These services are reported to include sign, color and name recognition.

A February 1985 survey of state mental retardation officials reported that 16 of 22 states reporting audit exceptions/disallowances by OIG had Medicaid payments for educational services as at least one of the grounds for those disallowances. One state mental retardation official summarized the situation as follows:

> "When a state furnished ICF/MR residents with 'active treatment services,' as required by federal law, we are being told such expenditures will be treated as non-allowable costs. On the other hand, should the state fail to provide such services, our ICF/MR facilities will be decertified for failure to comply with the statute and minimum federal standards. Talk about a "Catch-22!"

While ICF/MR standards require a certified facility to have written policies and procedures insuring the civil rights of all residents, numerous violations of these rights have been documented during certification surveys. Citations include:

> "The human rights of clients were not safeguarded and their dignity was not fostered as evidenced by the number of clients observed nude in buildings...Female clients were completely exposed to staff and visitors both male and female...A male client was in the dining room in his underwear, seated at a table. He was fully exposed and was masturbating while eating. Female clients were in close proximity at the next table. There was no attempt by staff to address the situation." (From a July, 1984 survey of Staten Island Developmental Center, Staten Island, N.Y.)

"One resident was observed to be restrained naked and lying on a bed without any sheets." (From a March, 1984 survey of Belle Chasse State School, Plaquemine, La.)

"I saw a young man asleep on the floor in the toilet stall with his pants around his ankles. I was advised that (the resident) does this all the time." (From an August, 1984 survey of J. N. Adam Developmental Center, Perrysburg, N.Y.)

"There was no evidence that a Resident's Bill of Rights existed." (From a April, 1984 survey of Newark Developmental Center in Newark, N.Y.)

"Each resident is not free from physical abuse as evidenced by numerous injuries..." (From a August, 1984 survey of Southwestern Developmental Center, Bainbridge, Ga.)

"A review of the accident and incident log noted numerous instances of clients sustaining abrasions, lacerations, discolored bruises, and ecchymatic breakdown." (From a August, 1984 survey of Letchworth Village Developmental Center, Thiells, N.Y.)

"A review of the clinical autopsy of three deaths for the months of February, 1984 and an analysis of two of those records raises questions about patient management." (From a March, 1984 survey of Belle Chaase State School in Plaquemine, La.)

"Lack of specialized programs for prevention of sudden, unexpected deaths ex: There were 61 deaths in 1983, 4 of 7 died from choking; there were 10 deaths in the first 1/4 of calendar year 1984." (From a August, 1984 survey of Letchworth Village Developmental Center, Thiells, N.Y.)

ICF/MR Medicaid dollars are spent in large institutions for the mentally retarded and there is little federal financial incentive for states to create smaller alternative settings.

ICF/MR facilities range in size from 4 to 2,000 beds. Over 90 percent of mentally retarded persons in ICFs/MR reside in facilities with 16 beds or more. Facilities with under 200 beds are often administered by the private sector, while those with 200 beds or more are usually public institutions. In 1982, 91,084 beds (or 66 percent) of the total number of ICF/MR certified beds were in institutions of 301 or more persons. Despite the fact that ICF/MR funds can be used for small residential settings, they are predominantly going to larger institutional settings. While the proportion of ICF/MR beds in institutions of 301 or more beds has decreased (from 81 percent in 1977 to 66 percent in 1982); the actual number of beds in ICFs/MR of 301 beds or more has increased (from 78,256 in 1977 to 91,084 in 1982).

In 1982 small residences of 15 beds or less represented only 7 percent of the total number of ICF/MR beds. By contrast, mentally retarded persons in small group residences throughout the country represented 21 percent of the total number of mentally retarded persons living in any sort of residential facility.

A study conducted by the National Association of State Mental Retardation Directors found that between 1977 and 1980 states spent $933 million for construction and renovation of mental retardation facilities. Eighty-three percent of that money was spent primarily to upgrade facilities so they would meet standards for ICFs/MR and qualify for Medicaid funds. Thus, states are in a position of having spent significant state dollars to upgrade institutional facilities. Naturally, they have a stake in keeping those institutions operational in order to capitalize on that investment, often at the expense of developing community alternatives.

Furthermore, many states are now in a position of facing increased expenditures if a resident of an institution is transferred to a small residential setting. In order to be certified for Medicaid reimbursement, an initial capital investment for renovations of a community residence is often required. If a community setting is not certified as an ICF/MR, the state would lose the federal Medicaid contribution. Thus, the transition from an institutional based delivery system to a community based living system represents a second set of initial capital investments.

Responding to questions from Senator Weicker, Secretary Heckler stated that "if a client is eligible for the ICF/MR level of care, we have no authority to say which specific setting is the most appropriate. The monitoring of level of care and placement decisions under Medicaid rests solely with the State."

This lack of a "least restrictive environment" standard for placement is contrary to several federal statues enacted after the 1971 Medicaid Amendment allowing federal reimbursement to ICFs/MR. P.L. 94-142, The Education for all Handicapped Children Act (1975) requires that education be provided to all handicapped students in the least restrictive environment, or the environment in which handicapped students are with their non-handicapped peers to the greatest extent possible. The 1975 amendments to the Developmental Disabilities Act included a section entitled "Rights of the Developmentally Disabled". This bill of rights requires that developmentally disabled persons be provided treatment, services and habilitation in the setting that is least restrictive of the person's personal liberty. Thus, while federal policy is establishing a standard of serving handicapped persons in the mainstream of society, it is at the same time providing incentives to do the opposite.

Congress was aware of this situation when it passed the Home and Community Based Waiver Authority in 1981. Title XIX was amended to allow the Secretary of Health and Human Services to approve the use of Medicaid funds for home and community-based services for the aged, the physically disabled, the mentally retarded and the mentally ill. (24) Under an approved waiver, services, other than room and board, may be provided to mentally retarded persons who, but for the provision of such services, would require the level of care provided in Medicaid-supported institutions. Regulations implementing the waiver provision include a cost formula which requires that a state's total Medicaid expenditures not increase with the waiver. (25) Services authorized by the waiver include case management services, homemaker/home health aide services and personal care services, adult day health, habilitation services, respite care services and other services as approved by the Secretary. States may be granted a waiver for three years initially. The waiver may be extended for an additional three years if services and conditions comply with program standards.

As of June 30, 1984, 33 waivers to serve mentally retarded persons had been approved for 30 states. For fiscal year 1984, plans submitted by states indicate that 15,114 MR/DD persons will receive waivered services. National cost data is not yet available on the waiver program.

Since the waiver program was authorized in 1981 and approved plans must be renewed every three years, waivers are just now coming up for renewal. States have expressed concerns regarding the terms of the renewal of the waivers and do not consider waivers as stable a source of funding as the traditional Title XIX Medicaid program, since it must be applied for separately, and is only authorized for a three year period.

On March 13, 1985, the final regulations governing the home and community care waiver were issued. These regulations create new obstacles for the states and fail to recognize the critical "active treatment" requirements of the ICF/MR program. The regulations declare that prevocational, and vocational training and educational activities may not be provided under the home and community based services waiver and explain that individuals "would not in the absence of such services, require institutionalization." The regulations further state that we have "excluded these services because they are not cost effective alternatives to institutionalization." These regulations imply that either persons who are developmentally disabled cannot benefit from such services or the only obligation the federal government has to meet to such persons is to provide custodial care. The ICF/MR program was created 13 years ago to negate both assumptions and create a new level of care that was not being met for persons with developmental disabilities in ICFs and skilled nursing facilities. The critical component of the level of care required by the ICF/MR program is for active treatment, a much higher standard to be met than custodial care. The implementation of these regulations may well deny mentally retarded/developmentally disabled persons needed opportunities for growth.

There is no formal mechanism between the Department of Health and Human Services and the Department of Justice for sharing information, coordinating activities, or making referrals.

The Department of Health and Human Services is the agency which administers the ICF/MR program. Under the authority granted to it by the Civil Rights of Institutionalized Persons Act (CRIPA), the Department of Justice has the responsibility to investigate institutions which have demonstrated a reasonable cause for believing that conditions exist which deprive residents of any rights or privileges protected by the Constitution or laws of the United States.

However, in a hearing before the Subcommittee on the Handicapped on Nov. 17, 1983, William Bradford Reynolds, Assistant Attorney General for Civil Rights, told Senator Weicker that he had not really been involved with HHS concerning ICFs/MR. Responding to questions from Senator Weicker in the July 1984 hearing, Secretary Heckler stated that HCFA staff and DOJ staff had met to discuss coordination between the two agencies.

In the fall of 1984 HCFA staff told Senate staff that they had met briefly with DOJ staff one year ago, but that there had been no follow-up. HCFA staff said that they were not, at that time, sending any information to the Department of Justice. At this briefing, one HCFA official said "the Justice Department takes too long" in conducting an investigation and cannot be relied on to respond to complaints relayed by HCFA.

Civil Rights of Institutionalized Persons Act

The U.S. Department of Justice continues to play a limited role in monitoring conditions in facilities for the mentally disabled as they relate to constitutional and federal statutory requirements. The few cases concluded by the Department's Office of Civil Rights suggests a continuation of the inactivity noted in previous congressional testimony.

Further, recently concluded investigations show that the Department's notice to the states as to findings have been sent up to 27 months after investigations are initiated. Such a lack of timeliness regarding matters determined to be egregious and flagrant abuses of the institutionalized mentally disabled potentially allows these conditions to fester, distorting the purpose of congressionally mandated intervention by the department.

In 1980, Congress enacted Public Law 96-247, the Civil Rights of Institutionalized Persons Act (CRIPA). (26) The Act provided the Department of Justice express statutory authority to investigate and initiate lawsuits on behalf of persons deprived of fundamental constitutional and federal statutory rights in state institutions. Fashioning the role played by the Department of Justice in cases brought to correct deplorable conditions and redress violations of rights, the Senate Judiciary Committee and the Conference Committee reports accompanying the legislation which eventually became CRIPA, both stated:

"One measure of a nation's civilization is the quality of

> treatment it provides persons entrusted to its care. The past decade has borne testimony to the growing civilization of this country through its commitment to the adequate care of its institutionalized citizens. Nowhere is that commitment more evident than in the actions of the United States Department of Justice." (27)

Since CRIPA's enactment, however, the role of the Justice Department in advancing the rights of the institutionalized has been questioned.

In 1971, in the case of Wyatt v. Stickney (28), Judge Frank M. Johnson invited the Attorney General to appear as litigating amicus curiae (friend of the court) to assist the court in gathering information on conditions and adequacy of treatment and care in an Alabama institution. Prior to the enactment of CRIPA, the Department of Justice participated in almost every major suit challenging conditions or violations of constitutional rights in mental institutions. Each case in which Justice had participated, according to the Senate Judiciary Committee report, had resulted in the court ordering immediate unconditional relief of conditions. Justice was also involved in such landmark cases as New York ARC v. Rockefeller (29), which resulted in a consent decree that ordered the depopulation of the Willowbrook State School for the mentally retarded and increased staffing levels, to provide for healthier conditions for those living in Willowbrook. Altogether, the Judiciary Committee report noted, Justice had been involved in more than 25 cases since 1971. In all of those cases, however, the Department's participation was either as amicus curiae or intervening plaintiff, i.e. a third party to the suit. Never had the Department initiated suit successfully. (30)

In fact, two courts in which the Attorney General had tried to sue state officials had rejected the suits. In those cases, U.S. v. Solmon (31) and U.S. v. Mattson (32), the courts held that, absent specific statutory authority, the Justice Department did not have standing to bring suit. To remove these barriers to Justice initiating suit, Congress enacted CRIPA. As the Judiciary Committee report concluded, it was important to give the Department this authority because:

> "The resources and skill which the Attorney General brings to such litigation cannot be matched by private counsel. The Justice Department's access to the investigative resources of the FBI, the technical advice of other Federal agencies, and the professional assistance of nationally recognized experts in the field of institutional care, enable it to develop a comprehensive record for adjudicating courts. The experience and expertise of Justice Department attorneys guarantees that litigation will be handled professionally, with a minimal expenditure of judicial time and resources. The presence of the Attorney General lends credibility to the proceedings and alerts courts, litigants, and the public to the seriousness of the charges. Finally, the Department provides the stability and continuity necessary to see litigation to its conclusion and to monitor implementation of court decrees. These factors combine to make the Attorney General an invalu-

> able aid to the judiciary and an indispensable advocate for the institutionalized." (33)

With respect to litigation as the means to redress institutional abuse the report concluded:

> "Neither the Attorney General nor the committee suggest that litigation by the Justice Department is an ideal method for eradicating widespread institutional abuse. It is costly, time consuming, and disruptive of the operation of State and local governments. Experience has shown, however, that it is also the single most effective method for redressing systematic deprivations of institutionalized persons' Constitutional and Federal statutory rights. Until such time as every State and political subdivison assumes full responsibility for protecting the fundamental rights of its institutionalized citizens, the need for Federal enforcement of those rights will continue."

After CRIPA's enactment, advocates for institutionalized individuals might have anticipated that the Department would use its resources to aggressively vindicate the rights of institutionalized persons. Under the Reagan Administration, however, some advocates have expressed disappointment with Justice's role.

Rather than the aggressive advocacy role that it historically had played, the Department has taken a very limited view of its role.

On Nov. 17, 1983, Senator Weicker chaired a hearing of the Senate Subcommittee on the Handicapped to examine allegations concerning the abuse and neglect of mentally retarded persons. Assistant Attorney General William Bradford Reynolds testified at that hearing concerning the Department's activities under CRIPA. At that hearing, Reynolds explained his interpretation of CRIPA and the appropriate criteria for judging the Department's activities as follows:

> "In my view, CRIPA represents the basic congressional reaction to and remedial prescription for a record of tragic abuse and frustratingly slow action in individual lawsuits brought on behalf of institutionalized persons. But it is important to note at the outset that CRIPA does not define the civil rights of those who are institutionalized. Rather, it provides limited procedural authority for the United States to act when he discovers institutional conditions so 'flagrant and egregious' that they violate the Constitution. As in many other areas, Congress left it to the federal courts -- ultimately the Supreme Court -- to determine what constitutes a constitutional violation.
>
> "The Supreme Court has addressed this issue most recently in Youngberg v. Romeo, 102 Sup. Ct. 2452 (1982). In holding that the Fourteenth Amendment's Due Process Clause affords protection to the liberty interest of institutional residents, the Court set forth substantive guidelines which we try scrupulously to follow. In Youngberg the Court held that mentally retarded persons who are institutionalized enjoy several Fourteenth Amendments Rights: (1) the right to adequate food, clothes, shelter and medical care; (2) the right

to personal safety; (3) the right to freedom from unnecessary physical restraint; and (4) the right to such training as is necessary to further their interests in safety and freedom from undue restraint. On the other hand, Youngberg did not hold that states were under a federal constitutional obligation to provide the treatment necessary to cure the disorder or remedy the mental condition that prompted institutionalization, a question specifically reserved for later consideration.

"Accordingly, I perceive it to be our job -- a duty which I welcome and fully believe in -- to use the authority provided by Congress in CRIPA to compel states and local governments to stop confining frequently helpless citizens in conditions that offend both conscience and Constitution. The congressional authority is carefully and plainly delimited. Upon receipt of a colorable complaint the Attorney General is authorized and required to notify the appropriate state or local officials, to conduct an investigation and, if the evidence gathered persuades him there is a violation of constitutional protections, to so advise the responsible officials and attempt to arrive at an agreed-upon plan that would correct the deficiencies. If that is not possible, the Attorney General may then bring court proceeding to obtain relief, upon his certification that all reasonable steps short of court action have been taken.

"Accordingly, under the congressional scheme the measure of success is not how many lawsuits are brought -- for time consuming litigation was one of the problems that concerned Congress -- but rather how many constitutionally intolerable situations have been remedied." (34)

Observers have criticized the Justice Department for its failure to diligently pursue enforcement of the rights of institutionalized persons by pointing out its limited use of its authority under CRIPA to bring lawsuits; for retreating and changing postions in suits previously filed; as well as taking a very narrow and limited view of its interpretation of court opinions articulating patients' rights.

One recent analysis of Justice Department activity in the field suggests that the Department is engaged in a concerted attempt to narrow the rights of the institutionalized mentally disabled.

The analysis was made by a former attorney with the Special Litigation Section of the Civil Rights Division of the Department, which has experienced a 100 percent turnover in the last two years:

> "The Department's eagerness to change long-standing positions suggests a politicization of the litigation and enforcement processes that inevitably makes it a less credible participant in them. Its interpretation of Youngberg and its willingness to use it as a prism through which all matters arising in institutional litigation are viewed forces it into the ignoble position of rejecting all previous knowledge in the field and turning a deaf ear to new

> and important developments. Thus, the Jackson treatment theory (where the Supreme Court said, 'At the least, due process requires that the nature and duration of commitment bear some reasonable relation to the purpose for which the person is committed.' ed.) is not viable, special masters are never appropriate, harm does not include regression, and community placement can never be constitutionally required, all because Youngberg did not explicitly sanction them. But, of course, these issues did not arise in Youngberg." (35)

Noting a philosophical gap between the Department and many of the advocates and critics of the Department, Reynolds at the hearing said:

> "A sizable group of advocates in the mental health field do not see the Federal Government's role as the limited but effective one I have described. Rather, they are genuinely committed to the notion that Federal courts should require all institutionalized persons to be held under the least restrictive possible conditions, with many feeling that all institutional confinement should be eliminated. Under this approach courts would not be limited to correcting the kind of debilitating and life-threatening conditions identified by the Supreme Court in Youngberg, but instead would examine under a minimally restrictive standard, every aspect of institutional life. This approach thus necessarily focuses on court proceedings looking toward meticulous, detailed decrees.

> "As a personal view, I too, favor deinstitutionalization wherever possible, but as a Government official I do not believe that either Congress or the Federal courts have provided the authority to seek such solutions. Under our Federal system I maintain that the choice of whether to have institutional confinement be made by State and local governments; only when the conditions actually provided are in violation of Federal constitutional provisions should the Federal Government, in the person of the Attorney General, intervene. And that intervention, as Congress has prescribed, is for the Attorney General to notify the State, investigate the conditions, attempt to negotiate and monitor a remedial plan and, if necessary, to bring legal action to achieve the necessary relief to eliminate the specific, identified constitutional violation." (36)

Reynolds rebuttal to his critics is to point out the number of investigations that his office initiated. At the Subcommittee hearing Reynolds reported the Department had initiated 18 investigations of mental health facilities since CRIPA's enactment.

Reynolds attached to his testimony a list of the facilities and a brief descriptions of the status of those cases. The dates of Justice notification to the state officials of their intent to investigate allegations and the name of the facilities were:

- Nov. 5, 1980-East Louisiana State Hospital, Jackson La.
- Nov. 5, 1980-Rosewood Center, Owings Mills, Md.
- Nov. 5, 1980-Feliciana Forensic Facility, Jackson, La.

- March 23, 1981-South Florida State Hospital, Hollywood, Fla.
- July 31, 1981-Dixon Developmental Center, Dixon, Ill.
- April 19, 1982-Manteno Mental Health Center, Manteno, Ill.
- April 9, 1982-Enid State School and Pauls Valley State School, Enid, Okla.
- June 16, 1982-Logansport State Hospital, Logansport, Ind.
- July 1, 1982-Atascadero State Hospital, Atascadero, Calif.
- June 24, 1982-Orlando Sunland Training Center in Orlando, Fla.
- Aug. 18, 1982-Spring Grove Hospital Center, Catonsville, Md.
- Oct. 4, 1982-Worcester State Hospital, Worcester, Mass.
- Nov. 15, 1982-Northville Regional Psychiatric Hospital, Northville, Mich.
- Nov. 29, 1982, Hazelwood Intermediate Care Facility, Louisville, Ky.
- Feb. 7, 1983-Elgin Mental Health Center, Elgin, Ill.
- May 13, 1983-Fairview Training Center, Salem, Ore.
- Oct. 6, 1983-Central State Hospital, Indianapolis, Ill.
- Oct. 6, 1983-South Carolina State Hospital, Columbia, S.C. (37)

At the time of the hearing, all of these investigations were pending; no final resolutions had been reached with the states and the Department had not used its authority to bring suit in any of the cases. In one instance, they had joined suit as plaintiff intervenor involving Feliciana Forensic Center. Reynolds described his record as follows:

> "Our experience shows that the conciliation process

> can work most effectively. Rather than waiting years for the court battles to unfold before real relief comes to those who are institutionalized, we have already, through CRIPA conciliation procedures, achieved a great deal of success effectuating the rights of institutionalized mentally handicapped persons.
>
> "For example, one of our cases had resulted in the closing of the Dixon Developmental Center for mentally retarded in Illinois. Following our investigation, the State authorities agreed that the conditions were constitutionally intolerable, and that the institution must be closed.
>
> "A similar result was negotiated in portions of an institution in another case. In three other cases, remedial plans have been submitted by the States, one we have approved, and are now monitoring, and we are reviewing the other two.
>
> "Three other investigations have been completed, and six additional ones are in progress. Moreover, we have notified two other Governors of our intentions to investigate. In two pending cases, local officials have obstructed our efforts to investigate, and litigation may well be required. A complete list of these activities is appended to my testimony." (38)

Commenting on the conciliatory approach of the Justice Department in response to a question for the record from Senator Weicker, wrote:

"As a result of Reynolds' policy of conciliation, not a single enforceable agreement to eliminate civil rights violations has been negotiated with any mental retardation institution anywhere in the country. He claims that the closing of the Dixon Developmental Center came "(as) a result of our investigation and conciliation effort." He should be ashamed to tell such a blatant lie to a Committee of Congress. As Reynolds is well aware, the state's decision to close that institution had little if anything to do with the federal investigation. Dixon was closed in response to the exposure of abuses at the facility by the media, the recommendation of the state's own mental retardation professionals, and the desire of Governor Thompson to make the facility a prison. The Justice Department had barely begun its investigation and had conducted no settlement discussions with state officials when the decision to close Dixon was announced. That announcement came as a complete surprise to everyone at the Justice Department, including the line attorney responsible for the investigation, who learned of it by reading the headline in a newspaper.

"Not surprisingly, Reynolds can point to no additional successful results concerning any matter pursuant to the Act. Such a record of inaction sends a clear message to the operators of state institutions that the federal government will no longer play an active role in the enforcement of the civil rights of American citizens confined in state institutions." (39)

Addressing Reynolds interpretation of the law and his view of the role of the Department, Steve Whinston, also a former attorney in the Special Litigation Section of the Department said:

> "For ten years, the Justice Department argued to courts that institutionalized mentally retarded persons had a constitutional right to be placed in settings which are least restrictive of their personal liberty. Thus, institution residents should, wherever possible, be moved to more normalized non-institutional environments where they will be more able to receive the training needed to achieve meaningful habilitative objectives. Suddenly, under Mr. Reynolds, this was no longer considered to be consitutional right. Instead, for the first time, institutions were acceptable for large numbers of persons."

Whinston also pointed out that the Department has even changed its position in lawsuits in which it had been an *amicus* and sought remedies which plaintiffs attorneys were unwilling to accept.

> "The whole orientation of the Justice Department's litigation in this field has changed from enforcing the rights of the handicapped to establishing what are the limits of a state's obligations to the handicapped. The first question I was often asked under this Administration was 'What can we do to support the defendants on this issue?'
>
> "This greater concern for the state than the plaintiffs manifests itself not only in the substantive positions taken

by the Justice Department but also in the litigation strategy it pursues. The most blatant example of this was Mr. Reynolds' decision to exclude plaintiffs, on whose behalf the Department was supposedly litigating, from settlement negotiations.

"This first happened in the landmark Wyatt case. There, Mr. Reynolds personally conducted negotiations with representatives of the State of Alabama from which representatives of the plaintiff and his own trial attorneys were excluded. The Justice Department eventually signed a separate agreement with the State that was unceremoniously rejected by the District Court.

"A similar tactic was pursued in a case on which I worked, the Mansfield Training School litigation. There, negotiations began in earnest in early 1983. As the May, 1983 trial date approached, the negotiations became difficult and contentious although discussions continued. At some point, I was advised by Mr. Reynolds through my supervisor that no matter what happened in the negotiations we would not participate in trial. I was instructed to prepare a separate settlement agreement to be signed by the State and the United States. This agreement was to be based on the State's latest proposal, which had been rejected by the plaintiffs, with certain key elements (a schedule of deinstitutionalization, outside monitoring of progress, and assistance to retarded persons involved in due process hearings) omitted. I was instructed to mail this agreement to the State's attorneys but to keep even its existence a secret from plaintiffs' counsel. The only reason such a document was not signed in that case was that the Connecticut Attorney General had the good sense to realize that it was legally irrelevant to sign a 'settlement' with Justice if he still had to litigate against plaintiffs.

"This overeagerness to settle, even to the extent of excluding plaintiffs from negotiations, is not a characteristic of an advocate. Rather, it demonstrates and illustrates the motivating concern of today's Justice Department -- to ease up on the states and to ease off on asserting the constitutional rights of the handicapped.

"Of course, this should not be. The handicapped are the most sympathetic and the least political of the Department's client groups. To support the handicapped one need not refer to divisive factors of race, religion or income. Handicapping conditions cut across all those lines. To support the handicapped one need not impose the Federal government on anyone's private life. Recognizing the rights of the handicapped exalts the values of the individual above the authority of the state. This should appeal to any administration, even a conservative one. But that has not been the case here. Their visceral ideological opposition to enforcing civil rights extend to all aspects of civil rights, even to the handicapped.

"This attitude has been recognized ir the field. The Justice Department, once a sought after ally of

> plaintiffs, is now shunned by plaintiffs. Its participation is no longer valued. Groups refuse to cooperate with Justice's investigations. In cases where Justice is already involved, plaintiffs employ tactics designed to keep Justice out of certain issues. In sum, the Justice Department under Mr. Reynolds has completely lost its credibility as an advocate for the handicapped. In my view, this is also beginning to happen with the courts as well. Judges recognize that Justice's views are tainted by partisan ideology rather than distinguished by legal scholarship. This process will take many years to correct even after Mr. Reynolds' departure." (40)

In discussions with Senate staff, Whinston's experience was confirmed by a plaintiff's attorney in the Mansfield case. He told Senate staff that the Justice Department had promised the court that it would use its resources to prepare witnesses and interrogatories for suit. This was before the change of administration. After the Reagan Administration took office, Department attorneys simply filed appearances in court but nothing more. Pointing out Justice's inclination to settle lawsuits, he stated that when the Department files suit or intervenes, they come in with the consent agreement already drafted.

On Jan. 9, 1985, Senator Weicker wrote to the Justice Department and requested information concerning complaints about conditions in mental health facilities received by the Department. The letter asked for an update on the Department's activities since the Handicapped Subcommittee's 1983 hearings. The following response was given to that request in a Feb. 5, 1985 letter from Justice:

> "We are unable to respond fully to your request but we can offer a brief explanation of how the Special Litigation Section reviews complaints and other information about alleged violations. The Special Litigation Section receives information about alleged constitutional or statutory violations in public and private institutions from many sources, including, for example, various requests from individuals to investigate private institutions, and complaints about conditions which do not reach the level of egregious or flagrant conditions contemplated by the Act. All of these complaints and other information about public institutions regardless of merit, are reviewed and dealt with appropriately. Those which on their face appear to describe legitimate or serious concerns are looked into further to determine whether formal investigation is required. The volume of information is so great and the level of seriousness so varied, however, that we cannot maintain records of each and every item of information that comes to our attention. For these reasons, it is not possible to retain or track each and every complaint or piece of information which the Section receives for its review."

The Department further reported that since the November 1983 hearing, seven of the 18 pending investigations/negotiations had been closed: In two instances, Rosewood, Md. and Logansport and Central State, Ind., consent decrees had been entered into with state officials. Previously, the Department had reported that at Feliciana in Jackson, La., a settlement had been reached among the parties and at Dixon Developmental and Orlando Sunland Training School, they had no further involvement because of progress by the state in correcting the deficiencies; and since the hearing, six more mental health and retardation centers were being investigated under CRIPA. Those facilities and the date of Department's notification to state officials were:

- Nov. 11, 1983-Ypsilanti Regional Psychiatric Hospital, Ypsilanti, Mich.
- Dec. 16, 1983-Wheat Ridge Regional Center, Denver, Colo.
- Feb. 22, 1984-South Beach Psychiatric Center, Staten Island, N.Y.
- May 1, 1984-Southbury Training School, Southbury, Ct.
- Nov. 30, 1984-Belle Chasse State School, Belle Chasse, La.
- Dec. 7, 1984-Fort Stanton Hospital and Training School, Fort Stanton, N.M.

In sum, as of February 1985, the Department had initiated a total of 24 investigations. Three of these resulted in consent decrees and five were closed. According to information supplied by the Department then, 16 of 24 investigations remain pending. Senate staff independently obtained two recent letters of the Department's investigative findings involving cases with negotiations still pending.

On Nov. 26, 1984, the South Carolina Department of Mental Health made public a letter from Reynolds to Governor Richard C. Riley concerning the Justice Department's findings from its investigation at South Carolina State Hospital. The investigation had commenced on Oct. 6, 1983. The findings included the following:

"Staffing and Staff Qualifications: Our consultants found serious deficiencies in the number of qualified physicians at SCSH. As of April 1984, 28 physicians were responsible for round-the-clock coverage of almost 1100 patients. Not all of these physicians were full time, and some were not qualified in certain areas critical to the proper medical treatment of mental health patients, such as the use of psychotropic drugs. Of the 28 practicing physicians, 18 are psychiatrists. While some had a manageable caseload of 20 to 25 patients, others were responsible for the psychiatric treatment of up to 60 to 80 persons. Similarly, there is an inadequate number of psychologists on the staff. As discussed below, these staffing deficiencies have unconstitutionally deprived SCSH residents of adequate medical care and treatment necessary to avoid undue risks to the patients' personal safety and to assure freedom from unreasonable bodily restraints.

"We also found inadequacies in nursing coverage throughout most of the hospital, especially during the evening and night shifts. While some wards apparently have better coverage than others, our consultants noted instances in which one Registered Nurse was covering up to 14 wards, including three forensic wards.

"In conclusion, we believe that the current complement of professional and direct care staff is not sufficient to assure that professional judgments are being exercised in decisions affecting patients at SCSH.

"Protection from Harm: The deficiencies discussed above have resulted in serious deprivations of the right of patients to be free from unreasonable risks of bodily harm. Patients suffering from severe and sometimes violent psychiatric disorders, who are inadequately or inappropriately treated and supervised, pose a significant danger to themselves and others. Our review of Patient Abuse Reports, dating from January 1982 through January 1984, and of Board of Inquiry records, dating from July 1976 through January 1984, fully supports our finding that these deficiencies subject the patients to unreasonable personal safety risks. These include risks of deaths or injury from patient assaults, aspiration of gastric contents, choking on food, suicide, and improper medical diagnosis and treatment.

"Use of Psychotropic Drugs: Our consultants noted serious deviations from accepted professional medical practice in the use of psychotropic drugs. Several physicians interviewed were not well trained in psychopharmacology. For example, a number evidenced difficulty in discriminating between tardive dyskinesia and extrapyramidal side effects. This creates a clear danger to patients since the appropriate drugs to treat acute extrapyramidal side effects might exacerbate the condition of tardive dyskinesia. Some physicians were not aware of the neuroleptic malignant syndrome which is a potentially fatal condition occurring in some patients receiving antipsychotic drug treatment.

"While the prescription of several drugs at one time may be appropriate in some circumstances, review of patient records and Board of Inquiry reports revealed numerous instances of inappropriate polypharmacy. Additionally, almost all the patients at SCSH whose charts were examined were on some form of medication, but in many charts the goals and indications for drug treatment were not clear and reasons for changes in medication or dosage were not articulated. These problems are compounded by the reliance on inadequately qualified and supervised direct care staff to administer medication. Overall, the prescribing, administering, and monitoring of psychotropic drugs at SCSH constitute a substantial departure from accepted professional practices.

"Restraint and Seclusion: Restraints have been ordered on a nonemergency PRN basis for extended periods without professional evaluation by a physician. In the case of the Forensic Unit, Ward 176, the practice of secluding virtually all patients PRN in nonemergency situations is an extreme example of improper medical treatment which involves SCSH's own standards for issuance of seclusion orders.

Treatment necessary to facilitate the ability of patients to function free from unreasonable bodily restraint is often not provided. The staffing deficiencies previously discussed contribute to the failure of SCSH to provide such patients with necessary treatment and thus to the concomitant improper use of seclusion and restraint.

"Dates of Occurrence: While it is possible that the above-described conditions have existed for a longer period, our review of records which you have provided, including Board of Inquiry reports, indicates that a pattern or practice of constitutional deprivations has existed since at least 1977."

On Feb. 27, 1985, the Michigan Department of Mental Health made public a letter from Reynolds to Governor James J. Blanchard concerning an investigation of Northville Regional Psychiatric Hospital. The investigation had commenced on Nov. 15, 1982.

The findings included the following:

"1. Staffing

"Staff deficiencies pervade all major disciplines at NRPH, and result in patients being deprived of minimally adequate medical and psychiatric services necessary to avoid undue risk to their personal safety and ensure freedom from undue bodily restraint. The number of qualified psychiatrists at NRPH is insufficient. The lack of qualified psychiatrists means that patients are subject to inappropriate medical treatment due to incorrect diagnoses, harmful medication practices, increased use of seclusion and restraints, and insufficient monitoring of nonphysician staff who are responsible for carrying out important medical procedures.

"NRPH is also severely lacking in the number of qualified psychologists, with only two psychologists responsible for over 1,000 patients. Consequently, important diagnostic assessments regarding patients' psychiatric conditions are not made, and treatment programs necessary to preserve patients' safety and freedom from undue bodily restraint are not provided.

"A nursing staff shortage presents a major problem at NRPH. While patient capacity is 1032, the census was 1100 on our last tour on July 25-26, 1984. The inadequate nursing staff was evident throughout our tours, with most wards over census and understaffed. During evening and night shifts one RN would have the responsibility of covering up to 2 or 3 buildings, containing between 4 and 6 wards, with up to 240 patients. The result is that the care being provided by the present nursing staff to the 1100 patients at NRPH is clearly inadequate and jeopardizes patient safety. Indeed, a professional staff member indicated that the present nursing staff was capable of providing rudimentary custodial care to only 700 patients. The nursing staff shortage also results in unqualified and inappropriately trained personnel carrying out important medical procedures, thereby increasing the threat of unreasonable risk of harm to NRPH patients.

"Our consultants found the above staffing shortages to result in severe deficiencies in NRPH's practices with regard to psychopharmacology, recordkeeping, seclusion and restraint, and the hospital's ability to provide treatment programs to those patients for whom such programs are necessary to ensure their protection from harm and freedom from unreasonable bodily restraint.

2. Medical and Administrative Practices

"Our consultants found that severe deficiencies exist in all areas of psychopharmacology at NRPH, including the prescribing, administering and monitoring of psychotropic drugs, as well as the hospital's recordkeeping practices in relation to the above.

"Drugs are most frequently administered at NRPH by resident care aides (RCAs) - attendant care staff. The insufficient number of RN's, as described above, means that untrained, unqualified, and inexperienced staff are dispensing potent medications, including intramuscular injections, under limited or on some shifts nonexistent supervision. This practice, which is a significant departure from accepted medical judgement, increases the risk of morbidity and mortality due to medication error. The fact that important medical procedures and treatment decisions are made in the absence of the exercise of qualified professional judgments by physicians and RN's subjects patients to unreasonable risks of harm to their personal safety.

"There is also a pattern at NRPH of a lack of documentation justifying the reason for the prescription of particular medication, patient response to the regimen of drug therapy, and changes in medication. Progress notes are frequently unavailable on identified problems and when they are available, they are often illegible. Additionally, the criteria upon which diagnoses are based are often not listed in the patients' charts and when diagnoses are made they are rarely reconsidered. Such inadequate recordkeeping makes it impossible to make medically appropriate and reasonably safe treatment decisions and is therefore a significant departure from accepted medical judgement.

"Another deficient psychopharmacological practice is the inappropriate screening and monitoring of drug side effects, particularly tardive dyskinesia (TD), an antipsychotic drug induced neurological side effect caused by long term treatment.

"3. Seclusion and Restraint

"Seclusion is widely used at NRPH, frequently without doctors' orders and sometimes without the involvement of any licensed medical personnel, demonstrating the absence of the exercise of professional judgement by qualified physicians and nurses in the use of this procedure. The most frequent reason for secluding or restraining NRPH patients is patient on patient abuse. Upon a review of patient charts and interviews with patients, our consultants determined that seclusion and restraint are used more for punishment or for the convenience of staff instead of for treatment. Our consultants could not identify any treatment programs afforded to patients to reduce or eliminate the need for seclusion or restraints. The found that the lack of staff, as outlined above, was a major factor resulting in NRPH's inability to provide necessary treatment to its patients in order to ensure them freedom from unreasonable bodily restraint, including seclusion. In the view of NRPH's own professional staff, seclusion and restraint are used unreasonably when treatment, if afforded, might obviate any need for its use.

"4. Protection from Harm

"Patients who suffer from severe and sometimes violent psychiatric disorders, who are inadequately or inappropriately treated or supervised, pose a significant danger to themselves and others. Our review of incident reports, dating from July, 1983 to May, 1984, supports our finding that the above deficiencies subject patients to unreasonable safety risks. These include attacks by patients on other patients or staff, self abuse, destruction of property, neglect of patients who are supposed to be under one-on-one observation, inappropriate medical treatment, and unreasonable use of seclusion and restraint. The deficiencies discussed above have resulted in serious deprivations of the right of NRPH patients to reasonable security and safety from harm, as well as freedom from unreasonable bodily restraint, including seclusion."

A section-by-section comparison of the remedies sought by Justice at the facilities reveals the general nature of the prescription "to bring each of these conditions to the minimum level required by the Constitution of the United States."

South Carolina: "1. Hiring sufficient numbers of qualified psychiatrists, and other trained professional and direct care staff to ensure, on a continuing basis, that patients are provided with minimally adequate medical care and are not subjected to unreasonable risks to their personal safety."

Michigan: "1. Hiring sufficient numbers of qualified psychiatric nurses, and other trained professional and direct care staff to ensure, on a continuing basis, that patients are provided with minimally adequate medical care and are not subjected to unreasonable risks of harm to their personal safety.

South Carolina: "2. Development of a system through which the appropriateness and safety of patient medical care, particularly psychopharmacological treatment, can be monitored. In this regard, the state should develop and enforce requirements for more stringent recordkeeping; for physician review and approval of assessments and decisions relating to medical care made by nonphysician staff; for recording complete and detailed background information and clinical observations relative to the medical care of patients; and for ensuring that there exists for each patient a record of the course of treatment anticipated and followed, including individual problems and treatment goals. Appropriate equipment to meet necessary medical emergency needs should be obtained."

Michigan: "2. Development of a system through which the appropriateness and safety of patient medical care can be monitored by an experienced and qualified staff. In this regard the State should develop and enforce requirements for minimally adequate recordkeeping and for physician review and approval of assessments and decisions relating to medical care made by nonphysician staff."

South Carolina: "3. Development and implementation of guidelines for the appropriate use of seclusion and restraint."

Michigan: "3. Development and implementation of guidelines for the appropriate use of seclusion and restraint."

South Carolina: "4. Development and implementation of such treatment programs as are reasonably necessary to promote patient safety and to keep patients free from undue bodily restraint, including seclusion."

Michigan: "4. Treatment programs must be professionally designed for those residents for whom such treatment will reduce or eliminate unreasonable risks to their personal safety and/or the need for undue bodily restraint. Immediate attention must be given to residents with self-injurious, aggressive, and other destructive behaviors by identifying them and implementing necessary treatment programs."

> South Carolina: "5. Development and implementation of measures adequate to assure staff compliance with hospital policies, protocols, and standards of job performance and behavior relating to the areas discussed above."

> Michigan: "5. Development and implementation of measures adequate to assure staff compliance with hospital policies, protocols, and standards of job performance and behavior relating to the areas discussed above."

Finally, after describing conditions that "threaten the health and safety of patients" at Northville in Michigan and "represent grave dangers to the health and safety of patients" at South Carolina State Hospital; and further, prescribing the hiring of "sufficient" staff and the development of unspecified "systems," "guidelines," "treatment programs," and "measures," the Justice Department recommended further meetings to develop plans of correction.

> South Carolina: "I would note that many of our findings and recommendations will come as no surprise to SCSH personnel. Many of these individuals candidly acknowledged the existence of areas requiring improvement. As previously noted, it was clear to us that SCSH employs many conscientious and dedicated staff who strive to provide the best care possible. We would be remiss if we failed to commend these persons for their very substantial efforts.
>
> "Again, we want to thank you for your cooperation.

Our attorneys will be contacting your office shortly to discuss this matter and to arrange for future meetings. They will be able to provide your staff with more detailed information.

"We would also be happy to make our consultants available to help the state formulate a specific and detailed plan for effectuating whatever corrective measures the state may choose to utilize in achieving constitutionally adequate conditions at SCSH."

Michigan: "I would note that many of our findings and recommendations will come as no surprise to NRPH personnel. Many of these individuals candidly acknowledged the existence of areas requiring improvement. It was clear to us that NRPH employs many conscientious and dedicated staff who strive to provide the best care possible. We would be remiss if we failed to commend these persons for their very substantial efforts.

"Again, we want to thank you for your fine cooperation. Our attorneys will be contacting your office shortly to discuss this matter further. They will be able to provide your staff with further detailed information. We would also be happy to make our consultants available to help the State formulate a specific and detailed plan for effectuating a legally binding, judicially enforceable agreement with the United States in achieving constitutionally adequate conditions at NRPH. Information about federal financial assistance which may be available to assist with the remediation process can be obtained through the United

States Department of Health and Human Services' Regional Office (Michele Harris, Director, Intergovernmental and Congressional Affairs; (312) 353-5132) and through the United States Department of Education by contacting individuals listed in the attached information guide. I look forward to working with you in a spirit of full cooperation to resolve these matters."

One of the facilities where the Department of Justice was investigating but had not initiated suit was against the Rosewood Center in Owings Mills, Maryland, coincidentally the same institution where Justice had been denied standing to sue in 1976 prior to enactment of CRIPA. In a Feb. 19, 1982 letter to Governor Harry Hughes of Maryland, Reynolds cited conditions that caused residents of Rosewood grievous harm. He cited their major areas of concern as: "abuse and neglect of residents minimally adequate environmental conditions and inappropriate placement of residents." The letter detailed the following specific findings on conditions at Rosewood by Justice investigations:

> "Rosewood has identified 777 persons in need of, and not receiving occupational therapy services.
>
> "Six severely handicapped female residents of Johns Cottage were allegedly raped by an outside intruder. It is undisputed that several of the residents had positive tests of gonorrhea of the throat right after the incident.
>
> "The charts of several male residents show the presence of venereal disease.

"Rosewood incident reports show that in June 1980, an employee of Gundry Building took a Rosewood resident off grounds without permission, and sexually abused him.

"In March 1980, nonconsensual sexual contact occurred between one resident, and at least one, and possibly three residents of the Stump Building. This incident occurred while the direct care staff person on the unit was sleeping.

"At least two deaths in 1980 were due in part to inadequate supervision by the Rosewood staff. As you probably know, Attorney General Sachs has reported on one of these deaths to the Maryland Humane Practices Commission.

"In February 1980, William Tillman managed to obtain a set of keys from a direct care staff person, and escaped from Rosewood; he was found near Rosewood by some passerby nine days later, dead from exposure to the cold. Two staff scheduled to be on duty the evening of Tillman's escape were not present. Robert Haynie, who was profoundly retarded, died on September 5, 1980, when a staff person left him unattended in a bath.

"Moreover, we have recently learned of the death of a resident of Benzinger Cottage. The resident apparently died as a result of being pushed down a flight of stairs. In our judgment, residents are exposed to serious harm at Rosewood.

"The vast majority of Rosewood clients reside in inadequate, deteriorating buildings. These residents are sterile, crowded, noisy places, which fail to provide even a modicum of privacy. The stench of urine is prevalent in a number of buildings.

"In the Pembroke Building, residents, many of whom have ambulation problems, were expected to cross over the puddle created by overflowing toilets, to reach the few working toilets. Severe heating problems in the Richards Building forced clients to sleep in their overcoats.

"During the recent cold wave, residents in Gundry, Richards and Pembroke Buildings were subjected to subfreezing temperatures.

"For many Rosewood residents, their environment not only fails to provide a homelike atmosphere, it jeopardizes their health and safety. For example, the 65 severely physically handicapped, and mostly wheelchair-bound residents of the second floor of the Wyse Building would have great difficulty evacuating the building in the event of a fire, and indeed, a fire did occur in Wyse last winter."

The letter suggested the following corrective actions:

"Rosewood must take steps to provide for full implementation of resident's individualized program plans.

"Needed professional and direct care staff must be hired.

"Rosewood must reduce the level of abuse and neglect in the institution.

"The institution must devise a preventive maintenance plan to deal with the deficiencies of the various buildings."

In the face of the abuses cited above, Reynolds closed the letter saying "we are willing to discuss these issues with you in greater detail at your convenience [emphasis added]."

On Jan. 17, 1985, Justice filed a consent agreement with the state of Maryland in district court to correct the conditions at Rosewood. This "settlement" came nearly three years after the letter to the Governor reporting Justice's investigation findings and nine years after the district court had dismissed a suit brought by Justice at the same institution.

The general principles of the agreement require that medical treatment, training and self-care skills of all residents (i.e. toileting, feeding) shall be made based on qualified professional judgments, all residents will be given appropriate care and medical treatment, all residents will receive reasonable training to prevent unreasonable risks of harm and undue restraint and that the physical environment be maintained to protect residents from unreasonable risks of harm or personal safety. To achieve these goals, the agreement calls for the state to take specific actions to: increase staffing, including physicians, psychologists, registered nurses, licensed practical nurses and direct care workers in ratios as set out in the agreement; and submit a plan within a set time frame on how it will achieve these goals.

It was Nov. 7, 1980 when the Justice Department notified Maryland officials of its intent to investigate the conditions and treatment of the mentally retarded residents at Rosewood. It was approximately 15 months later, that the Department wrote to the Governor conveying their findings. Not until Jan. 17, 1985, 50 months after initiating investigation and almost three years after informing the governor of its findings, did Justice reach a settlement and enter a consent decree with the state. The letter from the Department recognized that these conditions existed since 1974. Even though the 1976 lawsuit involved another administration, it has taken more than 4 years for this administration in its "conciliatory approach" to reach a settlement.

The time lag between the finding of unconstitutional conditions at Rosewood and the settlement designed to ensure that corrections are made shows, at the least, that the Department's conciliatory approach in this case and others has the potential to negate the type of federal involvement in basic health and safety issues envisioned and mandated in CRIPA.

The Future

Institutionalization and the Mentally Ill

The single most visible public issue regarding mental health in the nation today is that of homelessness. Public notions of "bums" and "hobos" as the infantry of the homeless have been largely replaced by the idea that many of these individuals are in fact refugees from mental health care, victims of psychiatric or legal mistakes, lured away from their safe institutional berths for unexplained reasons.

In Boston, an estimated 95 percent of the city's 2,000 homeless are said to be mentally ill by one estimate. In Washington, D.C., the estimate is up to 50 percent of the men and up to 90 percent of the women are mentally ill out of a homeless population of between 5,000 to 10,000. In New York City, thought to have the nation's highest homeless population, estimated at some 50,000, the percentage of mentally ill homeless is said to top 50 percent.

Nationally, a third or more of the 300,000 to 2 million homeless are said to have experienced some form of mental illness.

Over the last several years advocates for the homeless have noted the increasing numbers of those needing help who are mentally ill, many of whom are former residents of state mental hospitals.

"Over the last two decades, the wholesale and careless depopulation of mental institutions has perverted the implementation of the judicially-mandated right not to be confined if one is not a danger to oneself or others. By the hundreds of thousands, mental patients who have been aided by legal precedent and the advent of therapeutic drugs have been released to the streets, often with no more than a bus token.

This explosion of mentally fragile people returning to society occurs without the assistance and community support services that were ordered for them. The criminal lack of aftercare for such people has meant that their lives are often on display for the rest of us, contributing to one of the more popular images of the homeless: the woman or man, aimlessly wandering and animatedly talking, perhaps to an unseen companion." (41)

Allegations of careless and wholesale discharges from state institutions continue.

In December 1984, the Houston Post reported that some two dozen persons per week were taken from Austin State Hospital in Texas and "discharged" at a bus station in Houston. Most of the ex-patients were left with no money and no provision for food or shelter. A bus station security guard, the newspaper reported, escorted the twice weekly vanload to a local mission.

The Texas mental health system is under federal court order to hire more staff for the eight mental hospitals or discharge more patients.

Recently, the issue of the homeless has exploded into a full-scale public debate. Much of the debate is local, concerning the cost of services, the location of shelters in neighborhoods and the public policy of even allowing rootless individuals to roam a community.

The debate is also carried on between the legal and psychiatric professions, who have freely blamed each other for excesses over the years and in some cases, see this issue as the battleground of the next stage of care of the mentally ill.

The situation was brought into sharp focus this year, even before the annual spate of stories about the plight of the wintertime homeless, by a report published by the American Psychiatric Association. The report was entitled "The Homeless Mentally Ill" and it describes homelessness as one of the tragic effects of deinstitutionalization, a policy aided in a major way, the authors say, by the legal profession's zealous advocacy of patient rights. In the minds of the APA authors, lawyers and advocates share a heavy burden of blame for this failed policy.

That is, these advocates, in seeking to protect the rights of patients in the face of admittedly abusive conditions in mental hospitals by seeking their release, failed in a greater responsibility to safeguard the patients from some of the most debilitating effects of mental illness.

But remedying this past overbalance favoring the legal rights of mental patients should not be seen as an argument for reinstitutionalization of the mentally ill, several APA authors wrote.

The APA report notes that "Society has a limited tolerance of mentally disordered behavior, and the result is pressure to institutionalize persons needing 24-hour care wherever there is room, including jail." (42)

The director of the National Coalition for Jail Reform, said in a newspaper interview in 1983 that more than 600,000 mentally ill and retarded persons were in jails in 1982. "Moving mentally ill persons out of institutions in the 1970s may have been a good idea, but in many cases 'the money has not followed the people,' she said. 'For many, one kind of institution -- the mental hospital -- has been replaced by another institution -- the jail.'" (43)

Further, the APA report notes, "Some professionals now talk about sending the entire population of chronically and severely mentally ill patients back to the state hospitals, exaggerating and romanticizing the activities and care the patients are said to have received there. To some, reinstitutionalization seems like a simple solution to the problem of deinstitutionalization such as homelessness. But activity and treatment programs geared to the needs of long-term patients can easily be set up in the community, and living conditions, structured or unstructured, can be raised to any level we choose - if adequate funds are made available." (44)

But in the absence of alternative placements, the APA warns, public sentiment could propel reinstitutionalization. "There is a growing backlash from some concerned segments of the community about the lack of evidence that deinstitutionalization really works. If some corrections were made now, we might avoid a groundswell of opinion that could again make state hospitals the primary locus of care. Perhaps it is time that patients' rights groups and civil liberties lawyers focus more on the rights of patients to housing and care in the community...and less on forcing discharges from hospitals, which may ultimately put people on the street." (45)

A significant part of the discussion about solutions for the homeless mentally ill centers on the need perceived by some medical professionals to restrict the freedom and thereby staunch a psychiatric deterioration of this population. The issue is usually raised in the press and professional literature under the heading of asylum, a word associated with the "moral treatment" reforms in care of more than 200 years ago. The word also connotes institutionalization.

Dr. Charles Krauthammer, a psychiatrist and journalist, wrote recently that the homeless are overwhelmingly mentally ill and that sheltering them is only one solution. "There is a better alternative, however, though no one dares speak its name. Asylum. A place where the homeless mentally ill are taken and given food, shelter, hygiene and a sense of order in their lives."

He said the word "conjures up the snake pit," but actually "means taking people away to be cared for, whether they like it or not. That means taking control...and that means violating their rights, as currently defined...There will be a lot of thundering from civil libertarians. But it certainly can be done." (46)

Little more than a week later, the article was answered in the same newspaper by an attorney for the Mental Health Law Project, Leonard S. Rubenstein.

"The revived idea of asylum reflects a pessimism about society's willingness and ability to provide what a homeless person needs," Rubenstein wrote, "whether afflicted with a mental disorder or not. Bowing to that pessimism shows poverty of thought."

The reality of asylum, "is rigid confinement. The hospital may serve a function in providing acute, short-term care (and even for this there are often better alternatives), but for the long-term patient it remains at best a place of endless idleness, locked wards, isolation cells and deprivation of normal human contact." (47)

Away from this historic battleground of lawyers and psychiatrists, the landscape still forms a clear if uneven path to take the mentally ill from the streets to the hospitals.

The National Institute of Mental Health has said the latest figures available show approximately 50 percent of the nation's mental health money is spent on hospitalization and annual combined expenditures for state hospital care are approximately $4 billion.

In 1978, the President's Commission on Mental Health noted the incentives provided by federal spending: "Sometimes, inappropriate placements are forced upon the chronically mentally disabled by the restrictive nature of the regulations that govern distribution of Federal monies. A specific example is afforded by Medicaid funds which are not available to patients aged 21 to 65 in public or private hospitals. Thus, the level and type of care given to the chronically mentally disabled is frequently based on what services are fundable and not on what services are needed or appropriate. This not only does a disservice to disabled individuals but also distorts Federal expenditure patterns in various categorical programs." (48)

The recommendation made by the Commission was to provide care to the chronically mentally disabled regardless of age or place of residence.

Private health care money also provides a bias toward hospitalization, according to Dr. Charles A. Kiesler of Carnegie-Mellon University, who argued in a 1982 study against basing public policy on outdated "myths" surrounding hospitalization issues.

"People are being treated in more costly and less effective environments because it is the only treatment alternative the insurance plan will pay for, or at least pay for completely," Kiesler wrote. "A plan that considered the total cost and the patient's welfare might do better to set up financial and professional barriers against hospitalization rather than incentives favoring it."

Noting the dwindling national data base for hospitalization information, Kiesler compared statistics from NIMH and the National Center for Health Statistics.

The figures show "Mental hospitalization is increasing well in excess of the population rate," Kiesler found, although "the site of hospitalization has changed dramatically. The public image of mental hospitalization--the state mental hospital and the private mental hospital--now accounts for only 25 percent of the total incidence of mental hospitalization." (49)

Despite significant declines in the use of state/county mental hospitals, some 25 percent of total hospital days in the United States are for mental disorders. The figure has remained steady, Kiesler writes, because of the sharp, "linear" increase in the use of general hospitals as sites of hospitalization for mental disorders, especially those without psychiatric units.

Many professionals in the field call this shift of patients from state mental hospitals to other facilities "transinstitutionalization," or moving the site of care from one institution to the next as opposed to independent or quasi-independent living in the community.

"...thousands of former patients now live in nursing homes, board and care homes, adult homes and other institutional settings in the community. These mostly private, profit-making facilities serve the custodial, asylum and treatment functions that were once performed almost exclusively by state mental hospitals. The growth of what has been characterized as social control entrepreneurialism has thereby perpetuated the segregation of the chronically mentally ill in a new ecological arrangement in the community. Numerous reports also indicate that many other patients are now incarcerated in local jails and correctional facilities." (50)

Despite the general movement away from the state mental hospitals that occurred through the 1970s, "Data from the National Institute of Mental Health indicate that new chronic patients have continued to accumulate in state and county mental hospitals throughout the country, and statistics from New York and several other states show a reversal in the downward trend of the overall resident census in public mental hospitals. These trend reversals preceded the fiscal limits of the early 1980s, but a recent analysis suggests that current budgetary restrictions are likely to increase institutionalization." (51)

Furthermore, following the 1981 Omnibus Budget Reconciliation Act, which repealed specific funding for community-based treatment of the chronically mentally ill, recent policies could provide new incentives for hospital care.

> "In 1983 the Medicare Prospective Payment System was inaugurated. The enabling legislation authorized payment for hospitalization prospectively on the basis of preestablished rates for specific "diagnosis-related groups" (DRGs) rather than retrospectively on the basis of actual costs. Although designed to save Medicare resources in the Hospital Insurance Trust Fund by reducing the length and cost of hospitalization, the prospective payment system

> could also increase pressure on public general hospitals and long-term care facilities to provide for patients who might be discharged prematurely by other institutions on fiscal rather than clinical grounds. Such clinically irresponsible behavior would lead to a shifting of costs rather than a savings of resources and would counter the trend away from unnecessary use of institutional services. Because of a lack of experience in and general uncertainty about applying DRG based systems to mental disorders, psychiatric hospitals and psychiatric units in general hospitals were excluded from the prospective payment system until the applicability of DRG to inpatient psychiatric care and treatment could be evaluated." (52)

The incentive for various levels of hospitalization in one state, New York, was noted in the August 1984 draft report of the Governor's Select Commission on the Future of the State-Local Mental Health System:

> "Reliance on the Medicaid program as a principal source of funding has resulted in cost shifting among levels of government and in a highly medicalized mental health network. The Medicaid formula in New York is based on 50-25-25 percent federal/state/local cost sharing. Although federal regulations prohibit Medicaid reimbursement for persons 22 to 64 in State mental hospitals, it is available in general hospitals. Since the state pays 100 percent of the costs of care in State mental hospitals for this age group, there is a fiscal incentive for the State to promote inpatient

psychiatric care in general hospitals. Conversely, local governments have a fiscal incentive to promote inpatient care in State mental hospitals since the State pays 100 percent of such costs. Consequently, State and local mental health authorities may operate at cross purposes, with financial considerations taking precedence over patient needs. The Medicaid programs incentives for use of general hospitals as a primary site of treatment conflict with the basic tenets of sound community mental health care which emphasize alternatives to hospitalization." (53)

In the meantime, federally-supported outpatient care, the type of care sought most for the mentally ill by medical professionals and advocates alike, is largely unavailable.

In testimony prepared for the U.S. Senate Special Committee on Aging last December, John A. Talbott, M.D., president of the APA, said, "Without insurance, whether Medicare or Medicaid, outpatient treatment becomes virtually unobtainable. There are few dollars which would have been utilized at the state facility which follow the patient. Medicare and Medicaid (in most states) have severely curtailed benefits for the treatment of mental illness, in far lesser amounts than needed by the chronically mentally ill. Their pharmaceutical needs -- psychoactive medication in most cases -- is expensive and uncovered."

While financial incentives continue to push hospitalization and congregate care, leaving deficiencies in the community system, the numbers of the mentally ill are seen as growing by many professionals. There is an almost Catch-22 situation at work in the field. As underfunded community alternatives to hospitalization continue to be unable to handle the problems of the mentally ill, so are the state facilities that were originally supposed to wither after deinstitutionalization was seen as the new alternative. This is seen especially in the increase in short-term hospitalizations of young patients.

"Statistics have shown that only 10-30 percent of former hospital patients are employed at follow-up and that rehospitalization is high; 35-50 percent have been readmitted within one year after hospital discharge and 65-75 percent within five years." (54)

The so-called revolving door phenomena of frequent readmissions is especially frustrating to staff at many facilities, Senate staff found. These hospital employees said patients are frequently stabilized with medication and the hospital routine to the point where their psychiatric symptoms subside dramatically. Once released, however, many patients quickly "decompensate," fail to take medication, and once again enter an "acute" phase of their illness.

Returning to the hospital, they are met by an increasingly frustrated staff, especially direct-care staff, who are skeptical that the cycle can be broken.

"I'd like to see something like a habitual offenders law in the mental health code," said a direct-care aide in a Texas hospital. "Some sort of legal hold to make sure the patients comply with the rules and take their meds (medication)."

In Michigan, the mother of a 32-year-old man who had been hospitalized and released "many times," told Senate staff her son spent much of his time during discharges locked in his darkened bedroom. On two occasions, she said she was forced to call the police after her son became enraged, destroyed furniture, and threatened her. "I told him to take his medication, but he said he doesn't have to; he says he's got his rights from the mental health and they said he doesn't have to," she said.

A program director at a state hospital in Texas said that, too often, patients are discharged to themselves on strictly legal criteria. "Once you get a patient to the point where he's not a danger to himself or others, then they don't meet the hospital criteria, but that point is passed often long before there is any rehabilitation," he said.

One study noted that, "Even with the best possible outpatient care, many chronic psychiatric patients require admission, or readmission, for inpatient treatment. As federal and local fiscal cutbacks further overload already heavily burdened community support services, increasing numbers of patients and patients' families come to inpatient services requesting (or demanding) hospitalization for a patient who has never gotten well." (55)

In Colorado, Senate staff spoke with two of the four persons at the Ft. Logan Mental Health Center who are under contempt of court citations for refusing the order of a state judge to admit a court-committed individual.

The decision was a clinical one, the individuals said, and was made after a period of time when the high number of admissions of the facility had forced some patients to sleep on the floor.

Psychiatrist James Graves, formerly a consultant to the Public Health Service during the Kennedy Administration and described as one of the architects of deinstitutionalization, described the situation in the following manner: "Lots of people really thought we could end hospitalization, but nothing could be further from the truth. The chronically ill have suffered most. They've jammed up the community mental health services, but there aren't enough (local services) available." (56)

The lack of funding for community alternatives to hospitalization is but one of the jeopardies faced by those whose job it is to staff what is often the front lines of mental health care.

In Connecticut, Senate staff interviewed shelter operators in two cities who said their facilities were being jeopardized by bizarre or aggressive young individuals who disrupted the shelters with their behavior. One operator said his only option was to contact the police to transport the individual to a local hospital emergency room.

The Connecticut Hospital Association announced Jan. 21, 1985 it would lobby the Legislature to require state hospital admissions for patients legally certified by doctors. The association complained that patients often lingered for days in hospital emergency rooms waiting for open beds in state mental institutions.

An association official, in a recent press interview, said psychiatric wards of general hospitals and state mental hospitals had occupancy rates of 90 percent and above. General hospital officials reported patients waiting up to 14 days in emergency rooms for admission to psychiatric inpatient care and a "standing room only" situation in one emergency room holding area. (57)

Dr. Randall Stith, director of the Aurora (Colo.) Community Mental Health Center and director of the Colorado Centers and Clinics Association told Senate staff two forces are at work keeping demand for services extremely high.

> "We just can't keep up with the sheer population growth, so that's one of the major reasons for the increase in demands for services. The other reason -- and it's one we're working with other mental health centers to try and figure out -- is that while the numbers are increasing for us proportionate to that rapid population growth, the severity is increasing of the client we do see and are coming in there more seriously disturbed and that's a different issue and we're not real sure of what the elements of that are."

Stith's questions about the nature of the special problems of these so-called young adult chronic patients are echoed elsewhere by psychiatric professionals. There is a sense in the psychiatric literature and among professionals interviewed by Senate staff that this new wave of the mentally ill, without alternatives in the mental health system, is already breaking over the nation's state hospitals. "Today the 64 million babies born between 1946 and 1961 are between the ages of 21 and 36. They represent nearly one-third of the nation's population. Because of their overrepresentation in the population, the absolute number of young persons at risk for developing schizophrenia and, later, other chronic mental disorders is very substantial...the coming of age of children born after WW II is now having a marked impact on the psychiatric system." (58)

A social worker on a ward of a Texas state hospital said the newer patients have a longer period of time outside the mental health system to develop illness.

"We don't see patients in the hospital for a very long period of time anymore," she said. "These patients have character disorders, they look slick and streetwise and they frequently have medicated themselves with street drugs. The street is more forgiving, so we see them when they are sicker, but they aren't really chronic patients or passive or dependent."

A study of admissions to New York state adult psychiatric centers -- with 21,000 inpatients, the largest system in the nation -- showed "patients now being admitted are sicker, more hostile, and more difficult to treat."

The study concluded that "young people, especially young adult males, represent an increasingly larger proportion of the inpatients at state psychiatric centers. During the past five years young adult admissions to state centers have increased, as have their lengths of stay and the absolute number of young adults hospitalized at any point in time...

"These observations have major significance, particularly because the probability of release decreases greatly as the length of stay increases, and the young patients have many years ahead of them. The dimensions of their impact on the state hospital census, together with their larger impact on the rest of the service system, underscore the growing challenge that this special group presents to the field as a whole." (59)

The clinical director of one Colorado facility said the new, young patients, in many cases, have been sheltered by their families. "The families of these patients are just burned out and the patients have burned all their other bridges," he said.

A study of 294 such young adults by one group of mental health clinicians included a profile similar in tone to many such statements by mental health professionals.

"The presenting disturbances of these young adults and their social and treatment needs are disconcertingly similar, for they spring from the problems all these patients have in common: their acute vulnerability to stress, their difficulty in making stable and supportive relationships, their inability to get and keep something good in their lives, and their repeated failures of judgment, which can be seen as an inability or refusal to learn from their experiences. These patients provoke an uncommon amount of frustration and distress, not only from their relatives and associates but also from their clinicians and case-workers. They confound our efforts to treat them by conventional means, they evade yet repeatedly disturb our mental health programs, and they appear again and again in our psychiatric emergency services and police stations. Some, though not all, sojourn briefly in our psychiatric hospitals, where their names are likely to be well known, where they consume disproportionate quantities of staff time, where, recalcitrant children, they create more than their share of consternation, where they are the subject of multiple case presentations and interagency treatment planning conferences-only to be discharged back into lives that often prove once again untenable. These patients rarely reward our efforts with improvement. Instead they become, individually and collectively, our albatross. They are functioning persons only in a marginal sense; they manage their lives tenuously at best and disastrously at worst. They are discharged when their most acute symptoms have abated, but typically their remissions are incomplete." (60)

More importantly to state hospital direct-care workers, with whom psychiatric patients spend all but a fraction of their day, is the ever-present threat of violence by these younger patients.

"Many of these patients are characterized by assaultive behavior, severe overt psychopathology, lack of internal controls, reluctance to take psychotropic medications, an inability to adjust to open settings, problems with drugs and alcohol in addition to their psychoses, and, in some cases, self-destructive behavior. They often require highly structured community settings such as locked skilled nursing facilities of extended stays in state hospitals.

"Assessing the need for external control and structure is extremely important. When an attempt is made to manage such patients in less structured community settings, as in community mental health programs, these patients, though relatively few in numbers, tend to take up an inordinate share of the time and effort of mental health professionals. Further, although acting out defiantly, rebelliously, and violently may be an attempt to achieve independence and individuation, the community may not be able to tolerate the actions of these patients who do not demonstrate sufficient self control." (61)

At Dorothea Dix Hospital in Raleigh, N.C., a facility named for the famed 19th century reformer who encouraged construction of state hospitals, 49 percent of the 1981 admissions were patients in the age group 18-34. Of that group, the chief of the hospital's psychiatric services said, "They are totally difficult to deal with. They have the most provocative ways; most challenging ways. And, indeed, they release in most of us the most murky kinds of feelings, which are counter-productive." (62)

The frequent inability of staff to adequately control volatile hospital situations related to Senate staff by hospital employees, patients and advocates, is especially troubling in light of the predictions being made by mental health professionals.

One such prediction is that populations in mental hospitals could rise appreciably in the future.

Dr. Herzl R. Spiro of Vanderbilt University has established a set of variables that influence the numbers of patients likely to use state mental hospitals in the future. In a 1982 article, Spiro said "several of these variables have shifted significantly to increase the size of this population."

Citing information from a variety of research sources, Spiro concludes that "a renewed state hospital system is much needed to meet the anticipated increase in chronic, severely mentally ill patients."

The variables he cites include the expected increase in major psychiatric disorders as the population increases and the so-called baby-boom generation reaches the age of greatest risk for the disorders. Along with this increase is the decrease in less restrictive elements of the mental health system, such as emergency and outreach programs. The absence of these elements "may delay entry of some patients into the care system until their deleterious social complications are thoroughly established."

Spiro further cites data that shows rates of state hospital utilization rise during periods of economic hardship and unemployment. Also rising, he said, is the level of violence and the prospects that society will turn to secure public facilities as the answer to psychiatric patients exhibiting these behaviors. "Violent behavior, repeated substance abuse, and acting-out behaviors are more difficult to handle in community settings, nursing homes and general hospitals. Thus violent patients are likely to be transferred to state hospitals, often after being refused readmission to private facilities and general hospitals."

An evolving societal attitude, coupled with a severe shortage of alternatives, will place extra pressures on minority populations of the mentally ill, Spiro's research suggests.

> "The atrocious conditions in state asylums during the 19th century were largely produced by waves of European immigrants who generally resorted to public hospitals for treatment. Today the groups most frequently hospitalized in government institutions are blacks and Hispanics. High birth rates among both of these groups have produced an 'internal migration', resulting in demands for state hospital beds resembling those produced by the 19th century European immigrants...Liberalization of commitment laws and toleration of deviance probably reached its peak during the past 15 years. As the pendulum swings away from the extremely restrictive commitment laws and as some of the civil rights emphasis on personal freedom gives way to increasing emphasis on social control and order, patients are again likely to be sent to government institutions." (63)

In Texas, a state where the population jumped 27 percent between the 1970 and 1980 census, a special study panel appointed by the Legislature reported in January 1985 that the number of patients in state hospitals will jump 34 percent in the next five years barring major improvements in mental health services. Among the panel's recommendations were hundreds of additional community beds, a system of community case managers for discharged patients and new legislative authority to license what are often squalid boarding homes for the mentally ill. (64)

Last September, a pair of Harvard psychiatrists recommended the state of Massachusetts spend an estimated $25 million to construct six new mental health facilities to house approximately 1,000 patients deemed inappropriate for community care. (65)

If adopted, the proposal would mean an almost 50 percent increase in the state's institutionalized mentally ill population.

As an illustration of the changing nature of discussion on the issue of the state's role in mental hospitalization, a 33-member blue ribbon panel in Massachusetts recommended in 1981 that all five of the state's mental hospitals be closed within five years. Nearly half of the panel's members signed an alternative position paper questioning the ability of community resources to handle the discharged patients. (66)

Reports of innovative attempts at stabilizing young patients during an acute or crisis stage of their illness as a way of preventing the need for long-term hospital care have not been encouraging.

The Hutchings Psychiatric Center in Syracuse, N.Y. was constructed in the early 1970s, "designed to embrace the community mental health ideology and focus new programs on relatively young patients who were entering the mental health system for the first time."

The facility staff, "Imbued with optimism...intended not only to treat serious mental disorder but to prevent the scars of chronicity so widely associated with long-term hospital care." Despite these objectives, the facility faced increasing demands for service including a 20 percent increase in 1980 alone.

The reason suggested as "most responsible for the current bed crisis concerns the build-up of new long-stay patients. This is particularly true to those young adults who are difficult to place in community settings because of a history of arson or assault, or a diagnosis of mental retardation, or because they are being held under criminal proceeding. It is also true of older patients who need skilled nursing, which is often difficult to arrange, or other health-related care."

An analysis suggests "the problems and experiences of the Hutchings staff may reflect a trend that will probably influence most of the nation's mental health service providers." (67)

Such a trend may already be established. Figures compiled by the National Institute of Mental Health show that in 1978, for the first time since the 1950s, admissions to state mental hospital inpatient units began exceeding discharges. The total number of inpatients in these facilities has continued to decline slightly only because the death rate of patients continues to exceed net new admissions.

"In the heyday of deinstitutionalization it was thought that most of the chronically mentally ill who were warehoused in state mental hospitals would be discharged, and that those who remained would gradually die, making the back ward a historical curiousity. A concurrent replacement of that population, however, is preventing that from occurring. The new and intermediate long-stay groups illustrate that the process of institutionalization, as determined by length of stay, goes on.

> "...the marked slowing of the trend toward decreasing resident population marks yet another turning point for these institutions. Action taken by federal and state authorities at this turning point will possibly have more leverage than at other times, and could set the course of events for a long time into the future." (68)

Institutionalization and the Mentally Retarded

The trend for mentally retarded and developmentally disabled persons over the last 18 years has been one of gradual deinstitutionalization. When institutionalization was at its peak in 1967, 130 out of every 100,000 Americans were institutionalized mentally retarded persons. In 1982, 106 out of every 100,000 Americans were institutional mentally retarded persons. The rate of institutionalization is 18 percent lower in 1982 than it was in 1967.

The ICF/MR program reflects this trend to some extent. ICF/MR residents in facilities of 15 beds or less have grown from 1,725 in 1977 to 9,714 residents in 1982. However, as of 1982 these residents still represented only 6.8 percent of all ICF/MR residents. The other 130,970 ICF/MR residents remain in facilities of 15 beds or more, with 93,171 residing in institutions of 301 beds or more. The certified beds in these large institutions have continued to increase over the last 5 years (from 106,917 in 1977 to 140,684 in 1982). The ICF/MR program remains predominantly a program of institutionalization.

The ICF/MR program needs to be altered to provide an incentive to states to serve mentally retarded persons in the least restrictive environment. Ten years of experience with PL 94-142 has demonstrated the benefits of mainstreaming mentally retarded and developmentally disabled persons rather than segregating them. Where institutions were once thought to be the "state of the art" in care and treatment for mentally retarded/

developmentally disabled persons, today's knowledge tells us that a maximally mainstreamed setting is the "state of the art."

Safeguards against abuse and neglect, as well as the provision of active treatment need to be increased. Simply increasing staff, no matter what the residential setting, is not the solution. At one Connecticut institution visited by Senate staff, the certified buildings have twice the staffing ratio of the non-certified buildings. However, according to the superintendent of that facility, staff in certified buildings spend twice as much time doing paperwork as staff in non-certified buildings. Adequate staffing is essential, however staff must be trained to provide active treatment as their main job function. Increased technical assistance (such as that to be provided by the 12 new Developmental Disabilities Specialists HHS was directed by Congress to hire last year) is essential.

The deinstitutionalization of mentally retarded and other developmentally disabled persons has slowly begun. In order for this gradual shift away from institutions to community settings to be successful, reforms in federal policy are imperative. Incentives to provide adequate community settings need to be established. Mechanisms for monitoring care and services in community settings are critical in order to prevent the problems of abuse and neglect and lack of active treatment from following mentally retarded people from the institution into the community.

Mental Health Systems and the Federal Government

There is little new in revelations of substandard care and violence endured by mental patients in state facilities. Accounts in books, print and broadcast journalism and motion pictures have affirmed a widespread view in society that state mental hospitals are the lowest rung on the mental health care ladder and often, true "snake pits."

To a great extent, concern about care of the mentally disabled has been cyclical, sparked by rounds of publicity and indignation. Although these accounts are repetitious and frustrating to reformers, such stories about the plight of the severely mentally disabled through the decades move succeeding, evolving topics to the top of the public agenda in the field.

Social reform movements of the early 19th century brought to the fore the concept of "moral treatment," described in one account as the "belief that man could be perfected by manipulating his social and physical environment." (69) Construction of such facilities as the Friends Asylum in Pennsylvania and the Hartford Retreat in Connecticut around 1820 for "paying" patients led to concern for poorer patients who found a champion in Dorothea Lynde Dix. In the 1840's, Dix lobbied for the construction of state mental hospitals across the United States.

The resulting mix of public and private facilities led to a dual system of care as local poorhouses and even jails were able to transfer the financial burdens of care for chronic mental patients to the next level of government.

"Private sector facilities tended to specialize in providing treatment to wealthier, quiet, primarily voluntary patients, while the state asylums were left to provide long-term custodial care to poor, disturbed, involuntary patients. As the care system evolved over the next century, a two-class system emerged and became firmly entrenched. (State institutions') central purpose were defined by state legislatures in terms of custodial care and community protection; treatment was of secondary importance. Emphasis was placed on the custody of the largest number of patients at the lowest possible cost." (70)

In the first half of the 20th century, the population in state mental hospitals rose from some 150,000 to 512,000, a 240 percent increase and nearly twice the nation's rate of growth. In the following 25-30 years, the population shifts at the facilities was similarly dramatic. Between 1955 when the hospitals' population peaked at 559,000, and 1980, the census dropped by some 420,000 patients, a 75 percent decline. Also similar was the mix of public outcry and financial incentives that fueled the shifts.

"Deinstitutionalization policy took shape in response to civil libertarian litigation over the state hospital commitment process, the Medicare-Medicaid amendments to the Social Security Act of 1965, and the fiscal crises that enveloped the states in the early 1970s. Similar to the state care acts of the late 19th and early 20th centuries, the Medicare-Medicaid amendments allowed for buck-passing from one governmental budget to another--in this case from the states to the federal level. Within a short period of time, these fiscal and legal incentives led to the discharge of hundreds of thousands of mental patients from the state mental hospitals. CMHCs (Community Mental Health Centers) were almost totally unprepared or unwilling, or both to shoulder the responsibility for this chronic population." (71)

This shift of responsibility to the federal government was a move sought by reformers. A congressionally-mandated study by the Joint Commission on Mental Illness and Health, reported in 1961 after a five-year investigation that community mental health care was "a main line of defense in reducing the need of many persons with major mental illness for prolonged or repeated hospitalization." (72)

Certain chronic patients, the report said, would be kept in large state institutions along with victims of many chronic diseases, but most such facilities would be closed in favor of outpatient community care or psychiatric inpatient care in designated psychiatric wards of general hospitals. Two years later in October 1963, the passage of the Mental Retardation Facilities and Community Mental Health Centers Construction Act P.L. 88-164, threw the weight of Washington behind community controlled centers separate from state hospitals. As a result of the new policy, President John F. Kennedy told Congress, "reliance on the cold mercy of custodial isolation will be supplanted by the open warmth of community concern."

The legislation provided for the allotment of federal funds to the states for construction of community-based mental health centers. A state's allotment was based on population, extent of facility need, and financial need. Each state was required to develop a comprehensive mental health plan along with a list of priorities. States were also required to provide assurances that the services of centers would be available to all and that a reasonable amount of care would be provided to indigent persons.

The Community Mental Health Centers (CMHC) program was amended and extended several times. Between 1963 and 1980, CHMC program provided funding for 763 centers.

During the period, a significant change in the pattern of treatment of mental illness took place. In 1955, three out of four persons treated for mental disorders received treatment as inpatients. By 1980, three out of four persons receiving mental health care were treated on an outpatient basis. Large mental hospitals, for the most part, became places to provide long-term care for those with chronic mental illness, and were to serve as back-up facilities for community-based care, as well as for short-term hospitalization in periods of crisis.

As successful as the CMHC program had been in supporting the development of community facilities for mental health care, it had also become clear by the mid-1970s to Congress, the executive branch, and the mental health community that the program was failing to provide adequate mental health care to certain groups with special needs, such as chronically mentally ill persons, severely disturbed children and adolescents, and elderly persons, among others. Community mental health services had become located predominantly in middle-class areas, to the detriment of those living in rural areas, small towns, and the poorer sections of the nation's cities who were in need of mental health care, especially the chronically mentally ill who would have been hospitalized if not for deinstitutionalization.

Dr. M. Brewster Smith, a University of California psychologist and former vice president of the Joint Commission, said the panel's recommendation for this new national policy was based on "the sort of overselling that happens in almost every interchange between science and government...Extravagant claims were made for the benefits of shifting from state hospitals to community clinics. The professional community made mistakes and was overly optimistic, but the political community wanted to save money." (73)

Former commission staff director Jack R. Ewalt said the 1963 legislation resulted in states ceding most mental health responsibility to the federal government. "The result was like proposing a plan to build a new airplane and ending up only with a wing and a tail. Congress and the state governments didn't buy the whole program of centers, plus adequate staffing, plus long-term financial supports." (74)

The point has been made that in fact, the creation of community mental health centers as the successor to custodial care in institutions "exacerbated the plight of the chronic patient." First although construction of the centers encouraged deinstitutionalization, it also encouraged "previously untreated individuals" to seek mental health services, "largely ignoring the populations traditionally served by the state mental hospitals."

> "The problem for CMHCs was compounded by two additional factors... the concept of federal 'seed money;' with federal contributions decreasing annually, often meant that centers had to abandon poorer patients with a pattern of high service utilization (such as chronic patients) in favor of insured patients who might respond to brief interventions. Second, CMHC funding was through a federal-to-local community grant mechanism that avoided state involvement. This attempt to circumvent state mental health agencies in order to avoid control of CMHCs by 'institution-minded bureaucrats' also meant that the depopulation of state mental hospitals would proceed without coordination with the new centers." (75)

In 1977, President Jimmy Carter established a Commission on Mental Health to review the mental health needs of the nation and make recommendations to meet these needs. The Commission's report in 1978, found, among other things, that the CMHC Act had accomplished a great deal, but it also found that substantial problems persisted. The report noted that certain populations were underserved by the program, and that there were shortages of trained mental health personnel in certain areas. The Commission report made recommendations in eight broad areas: community support, services, insurance, personnel, basic rights, research, prevention and public understanding. In making 42 specific recommendations, with many subparts, on safeguarding rights, the Commission's task panel on legal and ethical issues stated that "the panel is also keenly aware that even the best intentioned efforts to deliver services to mentally handicapped persons have historically resulted in well documented circumstances of exploitation and abuse." The panel concluded that "perhaps the most important point that (we wish) to convey to the Commission is the importance of building a strong patients' rights and consumers' perspective into any reforms in the services system." (76)

To further stress this point in its report to the Commission, the task panel recommended initiatives be taken to promote legal advocacy.

Taking the panel's view, the Commission recommended the establishment of a legal advocacy system to protect the rights of mentally disabled persons receiving services. Even though the task panel had noted that there were many different and valuable kinds of advocacy systems to secure services and protection of clients rights, it stressed that its focus was on legal advocacy. Under the panel's definition, legal advocacy "... is directed toward establishing and enforcing the legal rights of mentally handicapped persons...(and) includes both consumer-oriented efforts to protect the liberty and other fundamental rights of mentally handicapped persons." (77)

The panel's recommendation to the Commission endorsed the creation of federal and/or state mechanisms to develop advocacy systems. It suggested the requirements for any advocacy system must be: "(1) able to respond to the legal needs of mentally disabled persons and (2) independent of providers of mental health and developmental disability services. An essential feature of such advocacy systems should be their effort to provide a continuity of legal services to such persons at all stages of their contact with the mental health system. Such advocacy systems should provide services at involuntary commitment proceedings and to institutionalized persons of all ages, as well as to community residents, in matters involving institutionalization (commitment, release, treatment issues), the fact of present or former institutionalization (availability of economic benefits, aftercare, denial of civil rights, employment, education issues), and other matters related to the existence--or perceived existence--of a handicap (domestic relations, contracts, wills, tenancy issues). In addition to attorneys (an "indispensable element in seeking and securing many types of remedies"), the advocacy system should be staffed by persons trained as "mental health professionals" (e.g., social workers and psychologists who provide advocacy services), by lay advocates, and by present and former recipients of mental health services, so as to provide a full-time staff with the necessary academic training and practical experience to provide comprehensive advocacy services for its clientele." (78)

In addition to providing legal counsel, the Commission also recommended a bill of rights for the mentally disabled, which articulated the following general principles:

- The right to treatment and habilitation and to protection from harm for all involuntarily confined mentally and developmentally disabled patients;
- The right to treatment in the least restrictive setting;

- The right to refuse treatment, with attention to the circumstances and procedures under which the right may be qualified;
- The right to due process when community placement is considered. (79)

In 1980, the Congress enacted the Mental Health Systems Act, P.L. 96-368 drawing heavily from the recommendations of the President's Commission.

In this Act Congress sought to integrate the state and federal roles in promoting community-based mental health care. Congress recognized that just as there was a need to integrate the mental health services between state and local governments, there was a need to provide a uniform system to protect patient rights in the health care delivery system. The Senate Committee on Labor and Human Resources, in its report on the bill which eventually became P.L. 96-368, established a bill of rights for the mentally ill and provided a system to protect those rights. (80) As reported by the Senate committee, the original bill intended to establish "a basic, though not comprehensive, set of rights for the purpose of assuring a greater measure of uniformity in their interpretation and implementation" among the states.

In setting forth these rights the committee report stated that it had carefully reviewed the state statutes and judicial rulings that had established many rights, "in varying terminology." But the rights found among jurisdictions "were highly inconsistent and often ambiguous." (81) The committee tried to clarify and consolidate a set of principles under the act in a bill of rights section, including the following:

- The right to appropriate treatment and related services in a setting which is most supportive and least restrictive of a person's liberty.
- The right to an individualized, written treatment or service plan.
- The right, consistent with one's capabilities, to participate in and receive a reasonable explanation of the care and treatment process.
- The right not to receive treatment without informed, voluntary, written consent, except in a documented emergency or as permitted under applicable law for someone who has been civilly committed.
- The right not to participate in experimentation in the absence of informed, voluntary, written consent.
- The right to be free from restraint or seclusion except in an emergency situation pursuant to a contemporaneous written order by a responsible mental health professional.
- The right to a humane treatment environment that affords reasonable protection from harm and appropriate privacy.
- The right to confidentiality of personal records.
- The right to have access to personal mental health records and have a lawyer or legal representative have reasonable access to records if the patient provides written authorization.
- The right to private conversations, reasonable access to telephones and mail, and to visitation during regular

visiting hours.

- The right to timely and meaningful information about one's rights at the time of and after admission.
- The right to assert grievances with regard to the infringement of rights and to have a fair, timely and impartial grievance procedure provided.
- The right of access to, including private communications with, any available rights protection service or qualified advocate.
- The right to exercise other rights without reprisal, including denial of appropriate treatment.
- The right to referral as appropriate to other providers of mental health services upon discharge.
- The rights described in this section should be in addition to, and not in derogation of, any other statutory or constitutional rights.
- The right to confidentiality of and access to records continues following one's discharge.
- No otherwise eligible person should be denied admission to a program or facility as a reprisal for exercising any of these rights. A program or facility is not required to admit a person who has previously refused to accept treatment, may discharge persons whose refusal of treatment prevents treatment, and need not treat persons admitted solely for evaluative purposes.
- The patient has a right that his attorney or legal representative have reasonable access to the patient/client, the facility at which the patient resides and, with

written authorization, the patient's medical and service records.

- Each program or facility should post the rights available to the patients.
- A patient who is incompetent may exercise rights through a court-appointed representative or legal guardian, chosen so as to avoid conflicts of interest.

Along with court decisions and state statutes, the Senate committee, in crafting the rights provisions of S. 1177, also took notice of other federal statutes, particularly the Developmental Disabilities Assistance and Bill of Rights Act.

Provisions of the MHSA were modeled after the Developmental Disabilities Act, which established a bill of rights for persons with developmental disabilities. Focusing on the conditions in institutions where disabled persons reside, the rights articulated in the Developmental Disabilities Act provide guidance for the service providers and were to be considered in addition to any constitutional or other rights afforded to all citizens. To assure that these rights were protected, the Act also required the states, in order to receive funding, to establish systems to protect and advocate the rights of persons with developmental disabilities.

Prior to 1978, the term developmental disability was defined to include mental retardation, cerebral palsy, epilepsy, and autism. The 1978 amendments to the Act, changed the definition to include people with specific major functional difficulties. Such difficulties include impaired capacity to care for one's daily personal needs, impaired capacity to understand and express language, impaired learning ability, and impaired independent mobility. While it was acknowledged that the mentally ill fit the new definition and could be covered by the Protection and Advocacy offices established by the states pursuant to the Developmental Disabilities Act, the focus of the P&A's of many states continues to be on services to mentally retarded and other developmentally disabled persons. Few state Protection and Advocacy Offices established pursuant to the Developmental Disabilities Act also serve patients in psychiatric hospitals.

With the Mental Health Systems Act, Congress attempted to meet the need for advocacy for the mentally ill. The bill provided funding for a grants program for protection and advocacy, similar to the Developmental Disabilities Act.

The design and funding mechanism for this program were different than under the Developmental Disabilities Act, but noting that some states may have successful offices and that existing P&A's may wish to expand and apply for grants for the mentally ill, the bill did not mandate a uniform design for the advocacy program. Certain criteria were established for eligibility for states. One criteria was that the advocacy office be independent of the service provider in the state. Similarly the bill required that the grant review process be separate and independent from any part of the Department of Health and Human Services involved in funding mental health service providers.

The committee report strongly urged that the Legal Services

Corporation, which had operated several experimental advocacy projects, be involved with HHS in reviewing requests for funding, and it stated the committee's intention that the program also be coordinated with Legal Services Corporation programs. The intent was to have a separate entity from service providers receiving requests for rights protection.

The bill as reported out of committee further provided that patients of facilities covered by the Act would be entitled to the assistance of counsel in bringing suit to vindicate violations of the bill of rights. Finally, in order to receive any funding for assistance under the Act, states were mandated to establish advocacy programs and the Secretary of Health and Human Services was given authority to discontinue funding for mental health centers if a state failed to enact necessary provisions establishing the basic rights delineated under the bill of rights section of the Act.

During Senate floor debate on S. 1177, Senator Robert Morgan of North Carolina strongly objected to the requirement that states adopt the bill of rights. He argued that states were as equally concerned as the federal government with preserving the rights of mental patients. Since the states had the primary responsibility for the care of patients, establishment of rights for patients was not a proper role of the Congress. Furthermore, it was asserted by other senators that several states had patient rights laws which were similar to those articulated in the MHSA. The claim was made that as many as 35 states had similar statutory provisions. (82)

Thus, an amendment to the bill was offered and accepted, changing the requirement that states adopt the bill of rights to a "sense of the Congress," which recommended that the states "review and revise" their statutes to conform with the bill of rights provision. Also, the section of the bill which gave individual patients the right to bring lawsuits to redress violations of the bill of rights was deleted.

In 1982, a report on a survey of states done by Martha Lyons, Martin Levine and Jack Susman concluded that the assumption by some senators that most states had similar laws protecting mental patients' rights, was "essentially in error." They found that both the number of states, 35, and the scope of the rights recognized by state statutes were inflated. While they found some state statutes recognized rights not included in the Mental Health Systems Act, they also concluded that to meet the standards recommended by Congress many states' laws would have to be changed significantly. (83)

The programs and authorities of the Mental Health Systems Act were scheduled to take effect in fiscal year 1982. The Reagan Administration, however, proposed in 1981, and the Congress enacted, a change in federal support for mental health services from the project grant approach of the Community Mental Health Centers Act and the Mental Health Systems Act to the Alcohol, Drug Abuse, and Mental Health Services (ADAMHS) block grant approach. The Omnibus Budget Reconciliation Act of 1981, P.L. 97-35, among other things, repealed most of the CMHC Act and the Mental Health Systems Act, including the newly authorized categorical program of protection and advocacy grants. The suggested bill of rights remained in the law, but with the repeal of the protection and advocacy grants, there is currently no federally-supported protection of those rights.

In June 1984, the General Accounting Office reported that federal support of the services comprising the ADAMHS block grant had declined 21 percent from $541 million to $428 million between 1981 and 1982. In fiscal year 1984, the block grant was increased nine percent to $462 million, and to $490 million in fiscal year 1985.

The Governor's Select Commission on the Future of the State-Local Mental Health System, a New York panel, said in its August 1984 draft report that federal support has declined even more substantially in recent times: "The recent economic recession resulted in federal policy that curtailed welfare expenditures. Not only has direct financial support in the Alcohol, Drug Abuse and Mental Health block grant been sharply cut, but in its SSI/SSD and housing policy, the Reagan Administration has withdrawn fiscal support from the states and localities. The federal government has placed the burden of care for the long-term mentally ill on the states. The pressure on the states has been enormous." (84)

Certain experimental protection and advocacy projects for the mentally ill were funded within the National Institute of Mental Health (NIMH) under their research authority in the late 1970s. In all, 28 demonstration projects were funded. An in-depth evaluation of 10 of those projects, conducted after they had been in operation for two years, came to the following conclusion: "...the general theme that emerges from this two-year undertaking is that advocacy services can and should be a permanent facet of any comprehensive mental health system." (85). Nevertheless, the Administration has not proposed, nor has Congress enacted, any protection and advocacy legislation subsequent to the repeal of the Mental Health Systems Act. Neither have any additional advocacy projects been funded under the research authority of NIMH.

In 1977, NIMH initiated the Community Support Program (CSP), to work with states and localities to improve opportunities and services for adults with chronic mental illness. According to NIMH, the program focuses specifically on those adults who are inappropriately institutionalized in hospitals or nursing homes, and the large number of such persons who are living outside of hospitals without adequate housing or life-support services. NIMH estimates there are between 1.7 and 2.4 million such persons at the present time.

The 1984 Alcohol, Drug Abuse and Mental Health Amendments authorize the Secretary of the Department of Health and Human Services to make grants to states and political subdivisions, and private nonprofit agencies for mental health services demonstration projects for the planning, coordination, and improvement of community services for chronically mentally ill individuals, seriously mentally disturbed children, and elderly individuals, and for research concerning such services. The Community Support Program has awarded modest grants to State mental health agencies to encourage placing greater priority on the needs of this population and to mobilize States and communities to improve opportunities for the chronically mentally ill, such as vocational rehabilitation and subsidized housing.

Considerable attention by commentators has been given to the necessity for advocacy systems to protect the rights of the mentally disabled. In their book entitled Legal Rights and Mental Health Care Herr, Avons and Wallace wrote:

> "Describing the attributes of mental-health advocacy can be controversial, especially given the great variety of types of advocacy and advocates who labor at this work. Mental-health advocates may be lawyers or laypersons; they may be well-trained recent college graduates, experienced community members, ex-patients, or trained of other professions. The training and supervision available to them and the forums in which they can advocate on their clients' behalf vary enormously from state to state and from advocacy project to advocacy project. In terms of personal commitment, aggressiveness, craftsmanship, and personality, advocates provide a spectrum no less broad than clinicians. Yet through all the differences in advocacy there are fundamental principles that must be maintained if advocacy is to be its own ethics and useful to its clients." (86)

As outgrowths of the attention to the structure, design and needs of patient advocacy offices several studies of existing advocacy projects around the country were done in 1980-1981. One evaluation of advocacy models sets out the following description of the four necessary elements of an ideal mental health advocacy system:

> "First, it should include a rights protection mechanism within the service delivery system designed to prevent violations of the rights of institutionalized clients, to operate a grievance system, and to monitor the ongoing delivery of mental health services, thus guaranteeing that remedial action will follow rights violations. Second, a comprehensive mental health advocacy system should include a legal advocacy mechanism independent of the service delivery system and capable of taking legal action against it in cases beyond the competence of the internal agency. Third, it should include a citizen advocacy mechanism in order to promote constructive relationships between mentally disabled people and members of the general public. Finally, a comprehensive mental health advocacy system should have as its ultimate objective training mentally ill and mentally retarded individuals to advocate on their own behalf whenever feasible, thereby minimizing the risk of paternalism in advocacy efforts and equipping mentally handicapped persons to be autonomous and self-reliant citizens to the furthest extent possible." (87)

The Courts and Protection of Patients' Rights

Introduction

In the last 20 years, there has been tremendous growth and expansion in the civil rights of the mentally disabled in state facilities. Clearly, gone are the days when patients left their rights at the door. Though basic rights have emerged from federal and state court decisions, statutes and administrative regulations, the law is still unsettled and continues to be redefined and refined. Just as the substantive rights recognized from state to state and among federal court jurisdictions vary, the systems to enforce those rights and the effectiveness of those systems are also diverse.

Advocacy of patients' rights in the courts is generally seen as a major contributing factor in deinstitutionalization. These advocates have also brought about significant changes in institutional conditions and the quality of care provided patients. Despite the progress in terms of judicial and legislative reforms, many of the deplorable and substandard conditions in public institutions still exist. With increased attention on the homeless mentally ill and some proposals for the relaxation of civil commitment standards, conditions in public hospitals will deserve more attention.

Judicial Decisions on Constitutional Rights of Mentally Disabled

Civil Commitment

The criteria and procedures on involuntary admission of an individual to a public mental institution is set by state statute. With the confinement to an institution being the most severe restriction to an individual's liberty and freedom of choice, constitutional challenges and legal reforms in state commitment statutes have often been the basis for broad reforms and recognition of rights of mentally disabled individuals. Legal theories from these cases and revisions of statutes have provided the foundation for other challenges to institutional conditions. Since the commitment process governs the flow of patients in and out of the hospital, it continues to be a hot topic of debate among mental health professionals, particularly between psychiatrists and legal advocates. It is in the context of commitment hearings that the tension and debate between the medical and legal professions continues.

The power of the state to involuntarily confine an individual to an institution derives from either its police power or its power as parens patriae (parent of the country).

Under its police power, the state is granted the authority to proscribe individual behavior in order to protect the public health, safety and welfare. In criminal cases the police power, however, is not unlimited; even someone charged with a crime is protected by procedural safeguards before they can be deprived of liberty. Under the police power, the state may involuntarily admit a mentally ill individual to a state mental institution if that person is dangerous to himself or others. In civil commitment, the police power is used when the purpose of commitment is to further a societal interest, such as protection for the public, rather than the interest of the person committed. But prior to some of the constitutional cases challenging commitment statutes, procedural protections provided prisoners were not applied to the civil commitment process. The second basis of commitment statutes served as the rationale.

Under the parens patriae power, the state can admit a person to a state mental institution, against his will, if the person is mentally ill and is in need of care and treatment. The rationale for the use of parens patriae was often viewed as a humanitarian one -- to protect those persons who are unable to protect themselves.

Two leading cases that established constitutional protections in the commitment process were Lessard v. Schmidt 349 E. Supp. 1078 (1972) and O'Connor v. Donaldson, 422 U.S. 563 (1975). The Lessard case provides an example of how easy it was to commit someone before state statutes were changed.

In this case, Alberta Lessard was picked up by police at her home in West Allis, Wisconsin and taken to a mental health center. After the police filed a petition requesting that Lessard be evaluated, she was detained at the center on an emergency basis. A judge issued two orders without her being present at the hearing and authorized her detention for 20 days.

After the initial emergency confinement, a series of evaluations took place, which were followed by 30 days additional confinement. Under Wisconsin statute it was possible for her to be involuntarily confined for a period of 145 days without benefit of a hearing. Lessard sued state officials alleging the Wisconsin statute violated her rights to due process including the denial of adequate notice of a hearing; the deprivation of her right to counsel; the violation of the privilege against self-incrimination and denial of speedy hearing.

The district court held that the Wisconsin civil commitment procedures did not provide adequate due process rights to those who were committed and ordered that numerous safeguards, including those claimed by Lessard, be instituted. The decision established at a minimum the following rights prior to involuntary commitment:

(1) notice of and time to prepare for proceedings;
(2) representation at the hearing;
(3) the right to be present at the hearing;
(4) a clear statement of the reasons for the commitment and
(5) a right to judicial review of and appeal of the commitment decision.

The second important case focusing on commitment standards was decided by the Supreme Court in O'Connor v. Donaldson. This case involved a challenge to the basis of a state statute on involuntary commitment.

Kenneth Donaldson had been involuntarily committed to

Florida State Hospital by his father. The father asserted that his son suffered from delusions. Under Florida statute, Donaldson was committed for care, maintenance and treatment. He had been confined for approximately 15 years and had repeatedly requested release to the care of friends who were willing to ensure his safety. His requests were always denied. He filed a petition in district court requesting his release and claiming that his constitutional right to treatment was violated because he had received none.

Evidence was presented at trial that Donaldson had never been dangerous to himself or others during this confinement (nor at any time during his life) and, if mentally ill, he had not received treatment. Members of the hospital staff testified that for substantial periods of time, Donaldson was kept in a large room with 60 other mental patients, many of whom were criminally committed.

The statute which authorized Donaldson's confinement, which had been repealed by the time of the Supreme Court's opinion, had allowed for indefinite custodial confinement of the mentally ill, even if they were not treated and their release would not be harmful.

The district court ruled in favor of Donaldson and the decision was appealed. The Court of Appeals affirmed the lower court's ruling and held that Donaldson had a constitutional right to treatment. The court noted that when the rationale for confinement is that the patient is in need of treatment, as in Donaldson's case, the Constitution requires that minimally adequate treatment be provided.

Although the Supreme Court vacated the right to treatment holding of the Court of Appeals, it held, however, that a state cannot constitutionally confine a non-dangerous individual who is capable of surviving safely in freedom by himself or with the help of willing and responsible family members or friends.

Since the decisions in these cases, state statutes have been reformed to meet the procedural requirements of Lessard and the substantive basis for commitment have been changed to meet O'Connor.

Actually, some state statutory reform predated these decisions. One such state was California, where in 1968, the Landerman-Petris-Short (LPS) statute revised the state's standards for commitment.

Under LPS, individuals may be involuntarily committed if they are mentally ill and are:

(1) dangerous to themselves

(2) dangerous to others or

(3) gravely disabled.

Lawyers and psychiatrists have long debated whether an involuntarily committed person should be committed under parens patriae power or the police power. The real reason behind involuntary commitment, the legal argument suggests, is the protection of society under the guise that the patient, although mentally ill, poses a dangerous threat. Adherents to the medical argument, on the other hand, believe that involuntarily committed patients are admitted because they are unable to care for themselves and therefore commitment is necessary. This tension between the professions can be seen in the context of the American Psychiatric Association's proposed model law to reform commitment statutes.

Dr. Allan A. Stone, former president of the American Psychiatric Association and chief draftsman of the model law, states that the model law draws from both medical and legal concerns and transcends both by placing the interests of the patient first. With respect to parens patriae commitment several states use the concept of "in need of care and treatment" as a standard for involuntary civil commitment.

Although the trend in recent years is to specifically require dangerousness for commitment or to require a likelihood of serious physical harm, the requirement of "in need of care" is still used. Two-thirds of the states permit the involuntary confinement of a person who is "gravely disabled," usually meaning that the person is unable, because of severe illness, to meet his basic needs for food, clothing, shelter and medical care.

Under the model law, parens patriae commitment would require that the patient suffer from a severe mental disorder, lack the capacity to make decisions concerning treatment, be treatable and likely to harm himself or others. Such persons would include those who are likely to suffer substantial mental or physical deterioration, as well as those who are dangerous or unable to care for themselves. The objective of this type of commitment is to allow commitment of many severely mentally ill persons ignored by current commitment laws, especially the homeless mentally ill.

With respect to the police power of a state generally, the concept of dangerousness to self or others is usually a standard for involuntary civil commitment in current law only if the dangerousness is caused by a person's mental illness.

The term "dangerousness" is not interpreted uniformly by the states, however.

Some states require an overt act such as an attempt or threat to do substantial harm; some require harm to property as grounds for commitment and others rely on a medical opinion that the individual is likely to do harm.

Courts normally rely heavily on testimony of psychiatrists and other mental health professionals to predict the potential dangerousness of an individual given that person's history.

The American Psychiatric Association believes that a psychiatrist cannot predict potential dangerousness of a person and thus confinement should not be based on that prediction. In the adverserial setting of commitment hearings, this issue has been problematic for psychiatrists who have felt patients needing treatment were not committed.

Under the model law, police power commitment would require a severe mental disorder, clear and convincing proof of likely dangerous behavior, lack of capacity to make decisions concerning treatment, and evidence that effective treatment will be provided. If this proposal is adopted, dangerous mentally ill persons housed in institutions who cannot be treated will be dealt with by the criminal justice system and will either be sent to prisons or other appropriate institutions.

In sum, the model law expands the reach of the mental health system to those who desperately need treatment and contracts its reach to those whom it cannot treat.

Right to Treatment and Right to Refuse Treatment

Legal advocates have focused much attention on the deplorable conditions in public hospitals. Through the courts, they have asserted several constitutional theories from which court rulings have developed constitutional rights for the mentally disabled.

One of the major principles in cases challenging the neglect of patients in state institutions is the right to treatment.

Dr. Morton Birnbaum, a physician and attorney, is recognized as the first person to articulate the theory that a person involuntarily committed to a state hospital has a legally enforceable right to treatment. Writing in the American Bar Association Journal in 1960, Dr. Birnbaum used a *quid pro quo* argument, essentially saying that when a patient is indefinitely confined to an institution for treatment, it is a violation of substantive due process not to provide treatment. Since then, the constitutional right to treatment has been an issue in many cases, although several states have recognized the right in their mental health codes. (88)

In 1966, one of the first cases to lend support to the right to treatment was Rouse v. Cameron, 373 F. 2d 451 (D.C. Cir. 1966). Although the case was decided on other grounds, specifically, that the District of Columbia statute recognized that the purpose of involuntary commitment was to provide treatment, the U.S. Court of Appeals acknowledged also that a right to treatment might be found in the U.S. Constitution under the 14th Amendment's due process and equal protection clauses as well as the Eighth Amendment's prohibition against cruel and unusual punishment, if the purpose of involuntary commitment was for treatment and none was given.

The first case to recognize a constitutional right of mental a patient to receive treatment was Wyatt v. Stickney, 325 F. Supp. 781 (M.D. Ala. 1971). In this opinion involving recommitment to Bryce State Hospital in Alabama U.S. District Court Judge Frank Johnson wrote, "the purpose of hospitalization for treatment is treatment. This is the only justification, from a constitutional standpoint, that allows civil commitments to mental institutions such as Bryce...To deprive any citizen of his or her liberty upon the altruistic theory that the confinement is for humane therapeutic reasons and then fail to provide adequate treatment violates the fundamentals of due process." (89)

Although the Supreme Court was presented with "a right to treatment" in O'Connor v. Donaldson, (90) the Court ruled that it was not necessary to decide the difficult issue of this right to treatment, having decided that Donaldson's confinement under

Florida statute simply because he was mentally ill was unconstitutional. The lower court, however, had received considerable evidence that the "Milieu therapy" provided by the Florida State Hospital was nothing more than custodial confinement. In its opinion the Fifth Circuit Court of Appeals stated that a patient had "...a constitutional right to receive such individual treatment as will give him a reasonable opportunity to be or to improve his mental condition" Donaldson v. O'Connor, (91) Again, when the case went to the Supreme Court, the Court specifically declined to address the question of a constitutional right to treatment.

The most recent case to be decided by the Court that involved the treatment of mentally disabled persons was Youngberg v. Romeo, 457 U.S. 307 (1982). While interpretations of Youngberg differ, it is agreed that it provides crucial input on the right to treatment.

The plaintiff in the case, Romeo, was a profoundly retarded and aggressive 33-year-old male, with a mental capacity of 18 months of age, who was involuntarily committed by his mother to Pennhurst State School and Hospital, a Pennsylvania state facility for the mentally retarded.

During his stay at Pennhurst, Romeo suffered injuries - both self-inflicted and inflicted by other patients - on over 70 occasions. The injuries included a broken arm, a fractured finger, injuries to sexual organs, human bite marks, lacerations, black eyes and scratches. His injuries then became infected, either from inadequate medical attention or from contact with

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human waste that staff failed to clean up. In addition, Romeo was shackled to a chair or a bed at Pennhurst for long periods of time. The staff claimed it was to control Romeo's aggressive behavior. Romeo's mother believed it was for staff convenience only.

Romeo's mother filed suit in the federal district court on his behalf alleging damages for her son being improperly shackled, the hospital's failure to prevent his abuse, and failure to provide adequate treatment for his mental retardation in violation of his rights under the 8th and 14th Amendments to the Constitution.

Romeo claimed specifically that he had a constitutional right to personal safety, freedom from undue bodily restraints and training or habilitation to ensure that right. The district court ruled that only the 8th Amendment's prohibition against cruel and unusual punishment was applicable to Romeo's circumstance and held against Romeo on that basis. Romeo appealed, and the Court of Appeals ruled that the 14th and not the 8th Amendment was applicable in involuntary commitment proceedings. The Appeals court reasoned that the 8th Amendment protection is limited to persons who are convicted of crimes and the 14th Amendment prohibits deprivation of life, liberty or property by the state without due process of law for all citizens and is therefore the appropriate standard to be applied in involuntary commitment proceedings. The court held that an involuntarily committed person has a constitutional right to safe conditions, freedom from personal restraint, and training to protect those rights.

The sole question presented to the Supreme Court on appeal, was whether these 14th Amendment protections applied to Romeo. At trial, the state had already conceded that mentally retarded patients have a constitutional right to adequate food, shelter, clothing and medical care under the 14th Amendment.

The Court first considered Romeo's claim to a right to safe conditions. The Court noted that the right to personal security is a protected constitutional right that cannot be extinguished even when one is imprisoned. Thus, if it is constitutionally impermissible to hold convicted felons in unsafe conditions, it is also unconstitutional to hold the involuntarily committed in unsafe conditions. The Court next considered the right to freedom from bodily restraint and again noted that this right has long been recognized.

The Court then considered whether Romeo had a right to training or habilitation to secure these rights. The Court referred to the American Psychiatric Association's brief which defined habilitation as focusing on training and development of needed skills for the mentally retarded. The Court determined that since the rights to safety and freedom of movement were recognized, training to protect these rights is also recognized. Upon holding that involuntarily committed mentally retarded persons have constitutionally protected rights to safe conditions, freedom from undue bodily restraint and habilitation to ensure those rights, the Court had to determine whether the state had violated these rights.

The Court upheld the standard applied by the Court of Appeals, by balancing the individual's interest with the state's interest and held that the Constitution only requires that the courts make certain that professional judgment was exercised at the time the decision was made.

The Court noted that only minimally adequate training as may be reasonable was constitutionally required and concluded that in deciding what is reasonable, courts must show deference to the judgment exercised by a professional.

Despite the fact that the Supreme Court's majority opinion did not address the issue of a general right to treatment in Youngberg, certain observations may be made. First, the fact that this general right was not discussed does not necessarily mean that the Court would not find such a right in another case. Such a right has been found in numerous lower court decisions (92) and the task panel on legal and ethical rights of the President's Commission on Mental Health has observed that "(w)hile the Supreme Court has not directly decided whether there is a constitutional right to treatment..., the overwhelming weight of legal authority is that (at least) all involuntarily confined mental patients have a 'constitutional right to receive such treatment as will given them a reasonable opportunity to be cured or to improve (their mental) condition.'" (93)

Second, the rationale of the majority in Youngberg could be used to support a finding of broad right to treatment. One commentator has noted that the liberty-based rationale used by

Justice Powell in the majority opinion may provide a basis for a broader right to treatment in three ways: (1) Justice Powell's requirement for training necessary to prevent violent or self-destructive behavior could arguably require broad training, such as basic self-help skills, since psychiatric studies apparently indicate that such training reduces violent behavior; (2) the liberty-based rationale could also be used, as was stated in a concurring opinion by Justices Brennan and O'Connor, "to include within the minimally adequate training required by the Constitution...such training as is reasonably necessary to prevent a person's pre-existing self-care skills from deteriorating because of his commitment" (94); and (3) the majority's reasoning could be used to imply rights that protect the patient's interest in release. (95) It was then concluded that "the majority's liberty-based rationale suggests that mental patients have a constitutional right to habilitative rather than merely protective treatment."(96)

Since the Youngberg decision, lower courts have not been consistent. Two opinions which have adhered strictly to the Supreme Court's analysis in Youngberg are Phillips v. Thompson, (715 F. 2d 365) and Society for Goodwill to Retarded Children, Inc. v. Cuomo (737 F. 2d 1239 (2nd Cir. 1984)).

In Phillips, the plaintiff, one of several hundred mentally retarded adults, resided at a privately-owned mentally retarded facility for the mentally retarded under a program sponsored by the State of Illinois. The residents were told of the facility's immediate closing and given 24 hours in which to move.

Representatives of the State Department of Mental Health instructed them to pack their belongings and moved them to state institutions.

Phillips sued the state alleging that his personal freedom was substantially restricted and that he was not receiving adequate rehabilatitive training. The district court ruled against Phillips and held that his liberty of movement was not illegally restricted in violation of the 14th Amendment nor was plaintiff denied training. Phillips appealed and the Court of Appeals affirmed. The court cited Youngberg in upholding the professional judgment standard applied by the lower court. The court determined that Phillips' liberty of movement was limited only by a reasonable requirement of caring for a large number of handicapped people in an institution as such requirements were determined by the professionals who operated the institution.

With respect to training, the court determined that Phillips was receiving adequate training prescribed by professional judgment.

In Society for Good Will, parents and residents of the Suffolk Developmental Center (SDC), an institution which houses mentally retarded persons, filed suit against the state of New York seeking improvement of living conditions, training and education of residents and transfer of residents into community placement. The district court ruled for plaintiffs and in addition, ordered 400 of the 1,200 SDC residents into community settings by 1987. Defendants appealed the entire ruling and order to the Court of Appeals for the Second Circuit. The court reversed the lower court's decision which had found for the plaintiffs by relying extensively on Youngberg.

With respect to plaintiffs' claim that the state violated their constitutional rights, the court held that, in light of Youngberg, the state must provide safe conditions to its residents, but held that the state did not unduly restrict plaintiffs' freedom of movement by either physical restraints or by failing to provide community placement. The court held that Youngberg in no way intended that mere residence in an institution violated constitutional rights for the mentally retarded. Further, the court cited Youngberg by stating that due process is satisfied if restraints are imposed on the mentally retarded in the judgment of qualified professionals and that courts should defer to this judgment.

With respect to training, the court held that a mentally retarded person has a due process right to training sufficient to prevent him from losing the basic self-care skills he had upon admittance to the institution. The court noted, however, that this does not include a right to training as would improve a resident's basic self-care skills beyond those with which he entered the institution and does not encompass skills that are not basic to self-care.

The decisions in Doe v. Public Health Trust of Dade County 696 F. 2d 901 (11th Cir. 1983), and Scott v. Plante, 691 F. 2d 634 (3rd Cir. 1982) on remand from the Supreme Court 102 S. Ct. 3474 (1982) 696 (F. 2nd 901 11th Cir. 1983) illustrate a broader interpretation of the Youngberg opinion.

In Doe, plaintiffs voluntarily admitted their minor daughter, Jane, to Jackson Memorial Hospital's adolescent psychiatric unit in Florida. At the time of admittance, plaintiffs were told by the hospital staff that they would not be able to communicate with Jane for the purpose of orientation and psychiatric evaluation. The Does consented and after one week attempted to communicate with their daughter. The hospital staff refused them access because Jane had not earned "privileges" of communication as required by her treatment regimen. The Does were also denied information on their daughter's treatment, approximate length of care and any possible side effects of medication. Hospital officials stated that the Does could seek a discharge of their daughter at any time if they did not wish to abide by the hospital's rules. The Does sued alleging that the "no communication rule" was non-therapeutic and medically unsound and that the right to communicate is constitutionally protected and cannot be abridged in exchange for service from the state. The district court ruled against the Does and they appealed. The U.S. Court of Appeals for the 11th Circuit reversed and held in favor of the Does. The court discussed at length the significance of the family and the importance of parental oversight. The court did not question the legitimacy of the professional judgment behind this program and said the program may well cure a patient. The court held, however, that the deference to medical judgment, as recognized in Youngberg, cannot impinge upon the constitutionally recognized parent-child relationship. In addition to these court findings of a broad right to treatment, commentators on the court's opinion in

Youngberg have suggested other ways to interpret the opinion to find a right to treatment. (97)

By setting what is commonly called a "professional judgment" standard for constitutional review of decisions in mental health facilities, to many the clear message of the court was that it would not get involved in the complex issues in only state hospitals. However, the approaches taken by lower courts in subsequent "right to refuse treatment" cases further exemplifies the state of flux that exists in mental health law.

Another major issue for mental patients in institutions concerns the ability or inability to refuse treatment. Because of the important role of drugs in the treatment of the mentally disabled, particularly the mentally ill, and the potential abuse of drugs as a disciplinary substitute for physical restraint and seclusion, the right to refuse treatment, specifically medication, has been called the most controversial subject in institutions and mental health law today. (98) Forms of treatment other than medication have also been at issue in cases involving this right. (99)

Although federal courts recognize mental patients' right to refuse treatment, controversy still centers on how the right should be implemented. The different approaches taken in court opinions interpreting the right typically reflect the classic professional clash in mental health law between the legal and medical professions. Whether a patient may be forced to take medication in an emergency? What constitutes an emergency? Whether the right applies for patients who have been adjudicated as being incompetent? All of these questions have been raised by courts trying to interprete and establish the parameters of this right.

One commentator has described the origins of the right to refuse treatment as follows:

> "The doctrine can be traced back over two hundred years to an English case in which the King's Court opined that medical surgery performed without consent to the patient constituted a tortuous assault. Modern decisions continue to impose liability for unconsented medical treatment, even where that treatment is, from an objective view, beneficial to the patient. The requirement of consent has long been considered necessary to protect not just the right of self-determination but also the very inviolability of one's person. Thus, treatment without consent constitutes unlawful assault and battery. (100)

The two leading constitutional cases on the right to refuse treatment are Rennie v. Klein (101), and Mills v. Rogers (102).

In both cases, plaintiffs asserted a right to refuse psychotropic medication and the lower courts recognized this right. Both were appealed to the Supreme Court and remanded in light of the Court's decision in Youngberg.

In Rennie, plaintiff, an involuntarily committed mentally ill patient at the Ancora Psychiatric Hospital, a state institution in New Jersey, sued several state officials and hospital personnel alleging that he had a constitutional right to refuse forcible treatment by antipsychotic drugs, which was violated by the state. The U.S. District Court recognized Rennie's right to refuse treatment in a non-emergency and noted that the final decision should rest with the patient. The court recognized that the constitutional right to refuse cannot be absolute and can be overruled if the patient is endangering himself or other patients.

The decision was appealed to the Third Circuit Court of Appeals which affirmed the district court's opinion in upholding Rennie's right to refuse treatment. The court's analysis included a least intrusive means test. The decision was again appealed to the U.S. Supreme Court. Previously, in Youngberg, the Court held that the standard for determining whether a mentally retarded patient could recover damages against a doctor or other professionals was whether the decision by the professional was such a substantial departure from accepted professional judgment as to show that the decision was unsound. The court did not adopt the least intrusive means standard of the appellate court, but instead remanded Rennie back to the panel for reconsideration in light of the Youngberg decision.

Upon reconsideration, the court of appeals held that Rennie had a constitutional right to refuse antipsychotic drug treatment and rejected the least intrusive means test because of Youngberg. But it may be constitutionally administered if in the exercise of professional judgment, such treatment is necessary to prevent the patient from endangering himself or others. The professional decision is presumed valid unless it is shown to be a substantial departure from the norm. The court accepted the professional judgment standard enunciated in Youngberg and added that the professional, in making his decision, should consider possible side effects to patients.

In Rogers, plaintiff and other involuntarily committed mentally ill patients at the Boston State Hospital in Massachusetts filed suit in U.S. District Court against state officials and hospital staff seeking to enjoin defendants from forcibly medicating plaintiffs with antipsychotic drugs against their will. The court ruled for plaintiffs and in making its decision, differentiated between two classes of plaintiffs -- those adjudicated incompetent and those who were not -- and two types of settings -- emergency and nonemergency situations. The court held that involuntarily committed mentally ill patients who were not adjudicated incompetent have a constitutional right to refuse treatment absent an emergency but may be forcibly medicated in emergency situations. An emergency was defined as a situation where there was a substantial likelihood of harm. Mental patients who have been adjudicated to be incompetent have a constitutional right to refuse treatment but the decision must be made by a guardian using a substituted judgment standard. A substituted judgment is generally considered to be a decision that an incompetent person would make for themselves if they were competent and is based upon the individual's religious beliefs and previously expressed opinions. The court noted here also that forcible medication was allowed in emergency situations.

The decision was appealed to the First Circuit Court of Appeals which affirmed in part and reversed in part. The appeals court held that involuntary commitment to a state institution does not preclude a patient's competency to make treatment decisions thus, a mentally ill patient has a constitutional right to refuse treatment through the use of anti-psychotic drugs. The court held, however, that in emergency situations, the physician could forcibly treat the patient if the physician exercised good professional judgment. The court defined an emergency to include situations where forced treatment was necessary to prevent substantial deterioration of the patient's mental illness.

The decision was appealed to the Supreme Court which remanded to the Court of Appeals. The court was instructed to determine the rights of the patients under state law which, the Supreme Court believed, gave adequate protection. The Court of Appeals in turn remanded to the Massachusetts Supreme Judicial Court to determine state law. The Massachusetts Supreme Court determined that, based upon state law, a mentally ill patient not adjudicated incompetent had a right to refuse antipsychotic drugs in a nonemergency. In an emergency, a physician could forcibly medicate a patient if medication is necessary to prevent imminent and substantial deterioration of mental health. The court further noted that a mentally ill person adjudicated incompetent had a right to refuse treatment, absent an emergency, exercised through a substituted judgment made by a judge. In an emergency, the decision to forcibly medicate is left to the discretion of the hospital staff.

The decision was again appealed to the Court of Appeals which held that the rights enunciated by the Massachusetts Supreme Court exceeded constitutional requirements although the court did not state what constitutional protection was recognized. The court noted that the substituted judgment can be made by a physician and not a judge and that a physician could forcibly medicate a patient if the physician believes the interests of the state outweigh the interests of the individual.

Since the Rennie and Rogers decisions, federal courts have been divided between medical and legal expertise in the right to refuse treatment, although the majority of cases appear to defer to medical judgment.

For example, in Project Release Provost, 722 F. 2d 960 (2d Cir. 1983), the Second Circuit found that a procedural scheme must allow for sufficient opportunity for professional input. In U.S. v. Leatherman, 580 F. Supp. 977 (D.D.C. 1983) a patient committed to St. Elizabeths Hospital in Washington, D.C. after a finding of not guilty by reason of insanity, was found to have a qualified right to refuse treatment. In deferring to medical judgement the court observed that "to require the courts to pass on such issues would embroil them in a never-ending controversy concerning medical judgments for which courts have neither the institutional resources nor the necessary expertise." (103)

Some other courts have taken guidance from the Supreme Court in Youngberg v. Romeo, in setting the parameters of the right to refuse treatment. For example, in Johnson v. Silvers, 742 F. 2d 823 (4th Cir. 1984), the court deferred to medical judgment. The

Court of Appeals found that an allegation that an involuntarily committed mental patient was being forced to take medication against his will constituted a claim actionable under 42 U.S.C. 1983 since such action gave rise to a protectible liberty interest. This liberty interest was found to be limited by the Supreme Court's holding in Youngberg, and in order to prevail the court found that the plaintiff must show that the defendant "has required him to take anti-psychotic drugs without exercising professional judgment."(104)

But, a few courts have required more extensive judicial involvement. For example, in Colorado v. Medina, 662 P. 2d. 184 (Colo. Ct. App. 1983), the court found that in the absence of an emergency, an involuntarily committed mental patient could not be given forcible medication without a court order.

In addition to the controversy over to what extent medical judgments should be deferred to, other issues have also given rise to controversy in cases discussing the right to refuse treatment. As was noted in several of the cases discussed above, generally, forcible medication has been allowed where there is an emergency situation. The cases have differed, however, as to what constitutes an emergency. Some cases, like the original district court decision in Rogers have defined emergency to mean a substantial likelihood of harm. Other cases, like the first court of appeals decision in Rogers, have used a broader definition of emergency to include the balancing of the patient's interests with those of the state.

In a situation very close to that of emergency treatment, courts have also dealt with the issue of whether a mental patient who has been determined to be dangerous to himself or others has a right to refuse treatment. Some courts have found that if a patient is determined to be dangerous, medication can be constitutionally administered without the patient's consent. For example, in Weiss v. Missouri Department of Mental Health, 587 F. Supp. 1157 (E.D.Mo. 1984), the district court found "a voluntary patient who presents a danger to himself or others has no constitutional right to refuse medication." (105)

Another issue where courts have differed concerns the decision to refuse or accept treatment if the patient has been declared incompetent. Generally, judicial decisions are split into two views. One view is that the decision should be made by an informed person such as a physician; the other is that the substituted judgment standard, i.e., what would the patient want if he or she were competent to decide, should be used. It should be noted that in either of these views, the person making the judgment could be a guardian, physician, or court.

A pending case on the treatment issue, Halderman v. Pennhurst, involves questions concerning whether a right to treatment or habilitation in the least restrictive alternative exists under federal statutes or the U.S. Constitution. The procedural history of this case has been complicated, (106) and it is presently on remand from the U.S. Supreme Court to the third circuit court of appeals. In connection with this remand, the Department of Justice filed a brief with the third circuit alleging that the district court erred in finding that the plaintiffs have a federal right to treatment in the least restrictive alternative. The brief reflects a change from the Department of Justice's previous postion.

The Department of Justice brief in Pennhurst framed the issue as "whether federal law provides involuntarily committed mental health patients a substantive right to 'habilitation' and, if so, whether the State must provide such habilitation in the least restrictive setting."(107) The Department of Justice brief argued that there is no substantive constitutional right to habilitation for involuntarily committed mental health patients beyond "the limited training right recognized in Romeo."(108) In addition, the brief contended that even if such a right were allowed, the least restrictive alternative analysis of the district court should not be allowed since in Youngberg the Supreme Court found that professional judgments are entitled to judicial deference. These two contentions will be discussed separately.

First, the Supreme Court has not addressed the issue of whether a mentally retarded person who is involuntarily committed to a state institution has a general constitutional right to treatment or habilitation. The closest the Court has come has been its holding in Youngberg that the state is under a duty to provide a mentally retarded institutionalized person "with such training as a appropriate professional would consider reasonable to ensure his safety and to facilitate his ability to function free from bodily restraints." (109) Thus, the position taken in the Department of Justice brief that there is not a general right to treatment in the least restrictive alternative is not directly contradictory to Supreme Court holdings. However, as was discussed previously, numerous lower court decisions have found that there is a general constitutional right to treatment in the least restrictive alternative. In addition, such holdings would not appear to be inconsistent with the Supreme Court's decision in Youngberg. As noted above, the liberty-based rationale used by the majority in Youngberg could be used to require broad rights in training such as basic self-help skills, prevention from deterioration and rights to protect the patient's interest in release.(110) The Department of Justice brief noted that its argument that there was no general right to treatment was based "[l]argely for the reasons articulated by Chief Justice Burger in his concurring opinion in Romeo."(111) The Chief Justice found in his concurrence that "...even if respondent could demonstrate that the training programs at Pennhurst were inconsistent with generally accepted or prevailing professional practice -- if indeed there be such -- this would not avail him so long as his training regimen was actually prescribed by the institution's professional staff." (112) The reasoning used by the Chief Justice was not accepted by the Court as a whole, although it should also be noted that the majority did not specifically reject this argument. The Department of Justice's reliance on such reasoning is, then, arguably not contrary to the Supreme Court's holding but neither is it required by the majority's opinion.

In Youngberg, the Supreme Court adopted the standard articulated by Chief Judge Seitz in his concurring opinion in the court of appeals decision in Youngberg that "the Constitution only requires that the courts make certain that professional judgment in fact was exercised. It is not appropriate for the courts to specify which of several professionally acceptable choices should have been made." (113) Thus, the Court appears to have rejected the least intrusive means standard and the brief of the Department of Justice apparently relies on this language to mean that "[o]nce appropriate state authorities make that decision as an exercise of professional judgment, the decision is not rendered constitutionally infirm because a less restrictive 'community placement' alternative may have been available but not chosen."(114)

Although the Supreme Court's language would appear to limit the concept of the least restrictive alternative, at least as applied to the right to treatment, the restrictive interpretation given the language in the Department of Justice's brief is not necessarily the only possible interpretation. In Rennie v. Klein, 720 F.2d 266 (3d Cir. 1983), the third circuit found that if it were to consider its previous opinion in Rennie (115) in light of Youngberg (as required by the Supreme Court), (116) the concept of the "least intrusive means" could not be employed. However, the same result, that is, a right to refuse anti-psychotic drugs, was obtained by the third circuit's majority using the professional judgment standard and noting that the extent to which the patient will suffer harmful side effects is one of the factors to be considered with the use of professional judgment. In a concurring opinion in Rennie, it was emphasized that although professional judgment is entitled to deference, such judgment "provides primarily a starting point for defining the constitutional rights at stake...The professional judgment of a physician acting with the power of state authority requires more than comparable professional decisions in a voluntary doctor-patient relationship. In the case of the forcible use of antipsychotic drugs, a state-employed physician must, at the very least, consider the side effects of the drugs, consult with other professionals and investigate other options available before that physician can be said to have discharged full professional judgment." (117)

In another recent decision, the second circuit in Woe v. Cuomo, No. 83-7269, No. 332 (2d Cir. Feb. 22, 1984), analyzed the meaning of deference to professional judgment as discussed in Youngberg and found that accreditation of a facility was an "exercise of professional judgment" entitled to deference under Youngberg. However, deference was not interpreted to mean that a court was barred from probing behind such accreditation. "Youngberg did not suggest that the judgment of the state's professionals was necessarily conclusive. On the contrary, the Court indicated that the testimony of Romeo's experts should have been admitted as relevant to the professional acceptability of the training he was receiving." To the extent, then, that the arguments in the Department of Justice's brief imply that courts lack the ability to look behind any professional judgment, these arguments would appear to be at odds with the recent cases of Rennie and Woe.

Summary

The Supreme Court in Youngberg v. Romeo, 457 U.S. 307 (1982), found that the state is under a duty to provide a mentally retarded institutionalized person "with such training as an appropriate professional would consider reasonable to ensure his safety and to facilitate his ability to function free from bodily restraints." (118) However, the Supreme Court's majority opinion did not go beyond this limited holding to consider whether there is a general right to treatment. The court did find that in determining what is reasonable, the courts are to show deference to the judgment of a qualified professional. In the remand of Halderman v. Pennhurst, the Court of Appeals for the Third Circuit was asked to address the issue of whether there is a right to treatment or habilitation in the least restrictive alternative based on federal statutes or the U.S. Constitution. In connection with this remand, the Department of Justice filed a brief alleging that there was no federal right to treatment in the least restrictive alternative. The arguments in the Department of Justice's brief were based on its analysis of Youngberg v. Romeo and relied on the reasoning presented in Chief Justice Burger's concurrence.

Although the arguments presented by the Department of Justice do not appear to directly contradict the Supreme Court's holding in Youngberg, they are a restrictive interpretation of the case and one which is contrary to arguments presented by commentators and several recent judicial interpretations. Previous to Youngberg, numerous courts had found a right to treatment for mental patients. In addition, the liberty-based rationale used to arrive at the majority's holding in Youngberg could be used to require broad rights in training, such as basic self-help skills, prevention from deterioration and rights to protect the patient's interest in release. Such reasoning finds support in the concurring opinion by Justice Blackmun in Youngberg.

The Supreme Court in Youngberg apparently set some limits on the least restrictive alternative theory by its emphasis on deference to professional judgments. However, the exact parameters of such deference are not clearly delineated in Youngberg. The Department of Justice brief interprets this deference to mean that once appropriate state authorities make a professional judgment decision, the decision is not unconstitutional because a less restrictive community placement might have been chosen. The restrictive interpretation given to the Supreme Court's language by the Department of Justice is not the only possible interpretation. Several recent cases have discussed the Youngberg requirement of deference to professional judgment and have found that it "provides primarily a starting point for defining the constitutional rights at stake..."(119)

In summary, then, the arguments made by the Department of Justice's brief in Pennhurst would not appear to be compelled by the Supreme Court's decision in Youngberg. They are one possible interpretation and can be described as a restrictive interpretation which could arguably be contrary to several recent judicial interpretations of Youngberg as well as contrary to the interpretation given Youngberg by some commentators.

FOOTNOTES

1. Governor's Task Force on Health and Safety at Cleveland Psychiatric Institute, State of Ohio, June 22, 1984, p. 28.

2. Joe Stebbins and Diana Dawson, "Mental Health in Missouri: A State of Stress", The Kansas City Star, Dec. 11, 1983, p. 21A.

3. Tina Lam, "Foreign-born doctors spark complaints about patient care," Ann Arbor News, Jan. 17, 1984.

4. Robert L. Pierce and Mike King, "Who cares for Kentucky's mentally ill?" Louisville Courier-Journal, Dec. 29, 1983, p. E7.

5. Robert D. Miller, M.D., Ph.D., "Public Mental Hospital Work: Pros and Cons for Psychiatrists", Hospital and Community Psychiatry, Vol. 35, (September, 1984) p. 930.

6. R.A.J. Review Panel, Third Report to the Court, May 1, 1983 - Nov. 1, 1983, 800 E. 8th St., Austin, Texas, pp. 28, 35.

7. R.A.J. Review Panel, Fifth Report to the Court, June 1, 1984 - Nov. 1, 1984, 800 E. 8th St., Austin, Texas, p. 14.

8. Governor's Task Force on Health and Safety at Cleveland Psychiatric Institute, State of Ohio, June 22, 1984, p. 29.

9. Clarence J. Sundram, J.D., "Obstacles to Reducing Patient Abuse in State Institutions," Hospital and Community Psychiatry, Vol. 35 (March 1984), p. 242.

10. Psychotherapeutic Drug Use: A Rx for Improvement--A Study of Selected New York State Psychiatric Centers, New York State Commission on Quality of Care for the Mentally Disabled, August 1983.

11. C. Thomas Gualtieri, M.D., and Robert L. Sprague, Ph.D., "Preventing Tardive Dyskinesia and Preventing Tardive Dyskinesia Litigation," Psychopharmacology Bulletin, Vol. 20, No. 3, (1984), p. 346.

12. In the matter of Christopher Dugan. A patient at South Beach Psychiatric Center, The New York State Commission on Quality of Care for the Mentally Disabled and the Mental Hygiene Review Board, January 1985, p. 12 and Attachment 1.

13. "Seclusion, Restraint Still Important Tools, Task Force Concludes," Psychiatric News, March 1, 1985, p. 1.

14. Roger Morris et al, "The officials are the last to know," Santa Fe Reporter, Aug. 29, 1984, p. 6.

15. A Review of Living Conditions in Nine New York State Psychiatric Centers, May 1984, New York State Commission on Quality of Care for the Mentally Disabled, December 1984, p. X.

16. *Wyatt* v. *Ireland*, No. 3195-N, M.D. Ala., Brief for Plaintiffs *and Plaintiff-Intervenors* , filed October 26, 1982, at 15.

17. Robert D. Miller, M.D., Ph.D., "Public Mental Hospital Work: Pros and Cons for Psychiatrists," *Hospital and Community Psychiatry*, (September 1984), p. 931.

18. Paul B. Lieberman, M.D., and Boris M. Astrachan, M.D., "The JCAH and Psychiatry: Current Issues and Implications for Practice," *Hospital and Community Psychiatry*, Vol. 35, (December 1984), p. 1209.

19. John H. Houck, M.D., "Regulation and Accreditation: The Pros and Cons for Psychiatric Facilities," *Hospital and Community Psychiatry*, Vol. 35, (December 1984), p. 1202.

20. *Wyatt* v. *Ireland* supra note 16 at 12-13.

21. Penny Barker, Project Officer, Health Standards and Quality Bureau, Health Care Financing Administration, Alvira B. Brands, Project Officer, National Institute of Mental Health, and Task Force Work Group composed of representation from Health Standards and Quality Bureau, and National Institute of Mental Health consultants, *Interpretative Guides for Medicare/Medicaid Surveys*, April 1980, p. 4.

22. *Wyatt* v. *Ireland* supra note 16 at 29.

23. Id at 36.

24. Public Law 97-35, Sec. 2176.

25. 46 C.F.R. 48535, October 1, 1981.

26. 42 U.S.C. 1997 *et seq*.

27. Senate Judiciary Committee Report to accompany S. 10, Sen. Rept. No. 96-415, 96th Cong. Sess., p. 1, and House Conference Rept. No. 96-987, p. 8.

28. 325 F. Supp. 781 (M.D. Ala. 1971), hearing on standards ordered, 324 F. Supp. 1341 (M.D. Ala. 1971), enforced, 344 F. Supp. 373 (M.D. Ala. 1974) aff'd sub nom. *Wyatt* v. *Aderholt*, 503 F. 2d 1305 (5th Cir. 1974), institutions placed in receivership, *Wyatt* v. *Ireland*, No. 3195-N (M.D. Ala. Oct. 25, 1979).

29. 357 F. Supp. 752 (E.D. N.Y. 1973).

30. Supra, note 13, at 2.

31. 419 F. Supp. 358 (D.Md. 1976), aff'd, 563 F.2d 1121 (4th Cir. 1977).

32. C.A. No. 74-138-BU (D. Mont. Sept. 29, 1976) aff'd, 600 F. 2d 1295 (8th Cir. 1975).

33. Judiciary Committee, supra note 13, at p. 27.

34. Enforcement of Section 504 of Rehabilitation Act: Institutional Care and Services for Retarded Citizens: Hearing before the Senate Subcommittee on the Handicapped of the Senate Committee on Labor and Human Resources, 98th Cong., 1st Sess., pp. 12-13, (1983) written statement of William Bradford Reynolds, Asst. Attorney General, U.S. Department of Justice.

35. Robert Dinerstein, "The Absence of Justice," Nebraska Law Review, (1984), Vol. 63, Number 4, p. 700.

36. Enforcement of Section 504 of Rehabilitation Act, id, p. 5.

37. Id., at pp. 23-26.

38. Id., at p. 6.

39. Id., at pp. 170-171.

40. Id., at pp. 198-204.

41. Mary Ellen Hombs, and Mitch Snyder, Homelessness in America: A Forced March to Nowhere, Community for Creative Non-Violence, 1982, p. 6.

42. The Homeless Mentally Ill, a Task Force Report of the American Psychiatric Association, September 1984.

43. Pete Early, "Jails are Becoming Dumping Grounds: Federal Government Advisory Panel Told," The Washington Post, June 17, 1983, p. A12.

44. The Homeless Mentally Ill, ibid., p. 67.

45. Ibid., p. 295.

46. Charles Krauthammer, "For the Homeless: Asylum," The Washington Post, Jan. 4, 1985.

47. Leonard Rubenstein, "The Asylum Will Not Help the Homeless," The Washington Post, Jan. 12, 1985.

48. "Task Panel Report on Deinstitutionalization, Rehabilitation and Long-Term Care," report to the President's Commission on Mental Health, U.S. Government Printing Office, 1978, p. 369.

49. Charles A. Kiesler, "Public and Professional Myths about Mental Hospitalization," American Psychologist, Vol. 37 (December 1984), p. 1336.

50. Joseph P. Morrissey, Ph.D., and Howard H. Goldman, M.D., Ph.D., "Cycles of Reform in the Care of the Chronically Mentally Ill," Hospital and Community Psychiatry, Vol. 35 (August 1984) p. 790.

51. Ibid., p. 791.

52. Ibid.

53. Draft Report, The Governor's Select Commission on the Future of the State-Local Mental Health System, State of New York, August 1984, p. 18.

54. H. Richard Lamb, M.D., and Roger Peele, M.D., "The Need for Continuing Asylum and Sanctuary," Hospital and Community Psychiatry, Vol. 35 (August 1984), p. 799.

55. Ira D. Glick, M.D., Howard M. Klar, M.D., and David L. Braff, M.D., "Guidelines for Hospitalization of Chronic Psychiatric Patients," Hospital and Community Psychiatry, Vol. 35 (September 1984), p. 934.

56. Tina Lam, "Caught in the middle," Ann Arbor News, Jan. 19, 1984.

57. Joan Barbuto, "Hospitals not equipped to handle mentally ill," New Haven Register, March 10, 1985, p. A1.

58. Leona L. Bachrach, Ph.D., "Young Adult Chronic Patients: an analytic review of the literature," Hospital and Community Psychiatry, Vol. 35., 1982, p. 190.

59. Abbott S. Weinstein, M.A., and Morris Cohen, Ph.D., "Young Chronic Patients and Changes in the State Hospital Population," Hospital and Community Psychiatry, Vol. 35, (June 1984), pp. 595-600.

60. Bert Pepper, M.D., Michael C. Kirshner, Ph.D., and Hilary Ryglewicz, A.C.S.W., "The Young Adult Chronic Patient: Overview of a Population," Hospital and Community Psychiatry, Vol. 32, 1981, p. 464.

61. H. Richard Lamb, M.D., "Young Adult Chronic Patients: The New Drifters," Hospital and Community Psychiatry, Vol. 33 (September 1982), pp. 466-467.

62. "Baby boom patients flood mental health facilities," The Durham Sun, Jan. 25, 1982.

63. Herzl R. Spiro, M.D., Ph.D., "Reforming the State Hospital in a Unified Care System," Hospital and Community Psychiatry, Vol. 33, (September 1982), p. 722.

64. Denise Gamino, "Mental Health System condemned in study by legislative panel," Austin American Statesman, Jan. 11, 1985.

65. John E. Gudeman, M.D., Miles F. Shore, M.D., "Beyond Deinstitutionalization. A new Class of Facilities for the Mentally Ill," The New England Journal of Medicine, Sept. 27, 1984, p. 832.

66. Jean Dietz, "Close regional mental hospitals, special commission urges in report," The Boston Globe, June 23, 1981.

67. John L. Sheets, M.S. W., M.P.H., James A. Prevost, M.D., and Jacqueline Reihman, Ph.D., "Young Adult Chronic Patients: Three Hypothesized Subgroups," Hospital and Community Psychiatry, Vol. 33, 1982.

68. Carl A. Taube, James W. Thompson, M.C., M.P.H., Marilyn J. Rosenstein, Beatrice M. Rosen, and Howard H. Holdman, M.D., M.P.H., Ph.D., "The Chronic Mental Hospital Patient," Hospital and Community Psychiatry, Vol. 34 (July 1983), p. 615.

69. Joseph P. Morrissey, Ph.D., and Howard H. Goldman, M.D., Ph.D., "Cycles of Reform in the Care of the Chronically Mentally Ill," Hospital and Community Psychiatry, Vol. 35 (August 1984),

70. Ibid.

71. Ibid.

72. Action for Mental Health, Final Report of the Joint Commission on Mental Illness and Health, Basic Books, 1961.

73. Richard D. Lyons, "How Release of Mental Patients Began," New York Times, Oct. 30, 1984, p. C1.

74. Ibid.

75 Joseph P. Morrissey, Ph.D., ibid., p. 791.

76. "Task Panel Report on Legal and Ethical Issues," report to the President's Commission on Mental Health, U.S. Government Printing Office, Vol. IV, 1978, p. 1363.

77. Ibid., p. 1366.

78. Ibid., p. 1368.

79. Report to the President, President's Commission on Mental Health, U.S. Government Printing Office, 1978, Vol. I, p. 44.

80. The Mental Health Systems Act, report of the Senate Committee on Labor and Human Resources to accompany S. 1177, Senate Report No. 96-712, 96th Congress 2d Sess. p. 35 (1980).

81. Ibid., p. 77.

82. Congressional Record, Vol. 126, S. 19494.

83. Mental Disability Law Reporter, Vol. 6, 1978, p. 78.

84. Draft Report, The Governor's Select Commission on the Future of the State-Local Mental Health System, State of New York, August 1984.

85. "Further Exploration of Advocacy Models for the Mentally Disabled," Human Services Research Institute, October 1, 1982, NIMH grant no. 1R18-MH36478-01.

86. Stanley S. Herr, Stephen Arons, and Richard E. Wallace, Legal Rights and Mental Health Care, 1983, pp. 9-10.

87. "Further Exploration of Advocacy Models for the Mentally Disabled," ibid., pp. 1-2, quoting Gerard J. Fitzpatrick, Mental Health Advocacy and Public Policy: Enforcing the Rights of the Mentally Handicapped in the Aftermath of Judicial Intervention, Mental Health Policy Monograph: Number 12, Vanderbilt University, September 1981, pp. 164-165.

88. 46 American Bar Association Journal 499 (1960).

89. Wyatt v. Stickney 325 F. Supp. 781, 784-785 (M.D. Ala. 1971).

90. 422 U.S. 563 (1975).

91. 493 F 2d 507 (5th Cir. 1974) 520.

92. See e.g., Wyatt v. Stickney, 344 F Supp. 387 (M.D. Ala. 1972); aff'd in part, rev'd and remanded in part sub nom. Wyatt v. Aderholt, 503 F. 2d 1305 (5th Cir. 1974); Nichols v. Laymon, 506 F. Supp. 267 (N.D. Ill. 1980). It should be noted that some cases have attempted to limit the right to treatment with regard to voluntarily confined mental patients or to institutionalized retarded children. See, e.g., Harper v. Cserr, 544 F. 2d 1121 (1st Cir. 1976).

93. "Mental Health and Human Rights: Report of the Task Panel on Legal and Ethical Issues, to the President's Commission on Mental Health, submitted Feb. 15, 1978," 20 Ariz. L. Rev. 49, 98, (1978).

94. Youngberg v. Romeo, 457 U.S. 307, 327 (1982).

95. "The Supreme Court, 1981 Term," 96 Harv. L. Rev. 62, 82-84 (1982).

96. Id., p. 84. Similar conclusions have been reached by other commentators. See e.g., note, "Beyond Youngberg: Protecting the Fundamental Rights of the Mentally Retarded," 51 Fordham L. Rev. 1064 (1983).

97. See "The Supreme Court, 1981 Term" 96th Hou. L. Rev. 62, 82-84 (1982).

98. See "Mental Hospital Drugs, Professionalism and the Constitution" Gelman, Sheldon, Georgetown Law Journal, August 1984, pp. 1725-1784, Legal Rights and Mental Health Care, ibid., p. 65.

99. See "Limiting the Therapeutic Orgy: Mental Patients' Right to Refuse Treatment," 72 NWUL, Rev. 461.

100. *Legal Rights*, ibid., p. 28.

101. 462 F. Supp. 1131 (D.N.J. 1978) (on motion for preliminary injunction); 476 F. Supp. 1295 (D.N.J. 1979) (classwide preliminary injunction); aff'd in part, modified in part, and remanded 653 F. 2d 836 (3d Cir. 1981); vacated and remanded for consideration in light of *Youngberg* v. *Romeo*, 457 U.S. 307, (1982), 458 U.S. 1119 (1982); 720 F. 2d 266 (3rd Cir. 1983).

102. (Originally titled *Rogers* v. *Okin*), 478 F. Supp. 1342 (D. Mass. 1979); aff'd in part, rev'd. in part, vacated in part and remanded sub. nom. *Mills* v. *Rogers*, 457 U.S. 291 (1982); *Rogers* v. *Commissioner of the Department of Mental Health*, 390 Mass. 489, 458 N.E. 308 (Mass. Supp. Jud. Ct. 1983); Rogers v. Okin, 738 F. 2d 1 (1st Cir. 1984).

103. 580 F. Supp. 977, 979 (D.D.C. 1983).

104. 742 F. 2d 823, 835 (4th Cir. 1984).

105. 587 F. Supp. 1157, 1161 (E.D. Mo. 1984).

106. The litigation began in 1974 and after a lengthy trial the district court found constitutional and statutory violations. 446 F. Supp. 1295 (E.D. Pa. 1977). On appeal, the third circuit affirmed most of the district court's judgment but based its decision on the bill of rights provision of the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. 6010. 612 F. 2d 84 (3rd Cir. 1979). The case was remanded to the district court for consideration of which patients could be served in community living arrangements. On appeal to the U.S. Supreme Court, the court of appeals' decision was reversed and remanded to determine if the order could be based on state law, the constitution, or section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794. 451 U.S. 1 (1981). On remand, the court of appeals affirmed its prior judgment in its entirety based on state law. 673 F. 2d 647 (1982). When the case went back up to the U.S. Supreme Court, the Court again reversed and remanded holding that the Eleventh Amendment prohibited the district court from ordering state officials to conform their conduct to state law. The Court found that on remand the court of appeals was to consider to what extent the district court decision could be based on the Eighth and Fourteenth amendments to the U.S. Constitution, section 504 of the Rehabilitation Act and other sections of the Developmentally Disabled Assistance and Bill of Rights Act, 42 U.S.C. 6011, 6063.

107. *Halderman* v. *Pennhurst*, Nos. 78-1490, 78-1564, 78-1602, *Brief for the United States*, filed April 24, 1984, at 7. (Herafter referred to as DOJ brief.)

108. Id., p. 8.

109. *Youngberg* v. *Romeo*, 457 U.S. 307, 324 (1982).

110. Few cases since *Youngberg* have specifically addressed the issue of the right to receive treatment although several have discussed deference to professional judgment. In *Phillips* v. *Thompson*, 715 F. 2d 365 (7th Cir. 1983), the seventh circuit found that "...*Youngberg* teaches that, at the most, the class members were entitled to minimally adequate training as is reasonable in the light of their interest in freedom of movement and that deference must be shown to the professional judgment of those directing the operation of the institution." This statement was not elaborated on by the court although it seems to indicate that the seventh circuit would interpret *Youngberg* in a more restrictive manner than commentators have suggested.

111. DOJ Brief at 7.

112. *Youngberg* v. *Romeo*, 457 U.S. 307, 331 (1982).

113. Id. at 321, citing 644 F. 2d at 178.

114. DOJ Brief at 11.

115. *Rennie* v. *Klein*, 653 F. 2d 836 (3d Cir. 1981).

116. *Rennie* v. *Klein*, 102 S. Ct. 3506 (1982).

117. *Rennie* v. *Klein*, 720 F. 2d 266, 271-272 (3d Cir. 1983).

118. *Youngberg* v. *Romeo*, 457 U.S. 307, 324 (1982).

119. *Rennie* v. *Klein*, 720 F. 2d 266 (3d Cir. 1983).